



## DOCTOR OF HEALTH (DHEALTH)

### A Narrative Exploration into the Experiences of Mothers living with HIV in Ireland

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**A NARRATIVE EXPLORATION INTO THE EXPERIENCES OF  
MOTHERS LIVING WITH HIV IN IRELAND.**

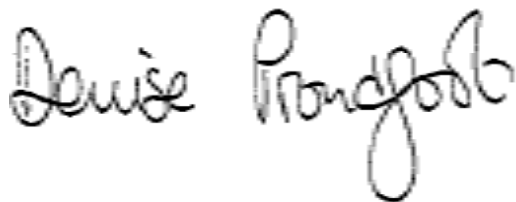
**DENISE PROUDFOOT**

**A THESIS SUBMITTED FOR THE DEGREE OF PROFESSIONAL  
DOCTORATE IN HEALTH.**

**June 2014**

**DEPARTMENT OF HEALTH, UNIVERSITY OF BATH, UK.**

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A handwritten signature in black ink, reading "Denise Prongob". The script is cursive and fluid, with the first name "Denise" and the last name "Prongob" written in a single continuous line.

## Acknowledgements

*The idea to conduct research with mothers who are living with HIV formed when I was working as a specialist HIV mental health nurse in London during the late 1990s. I had a caseload of HIV positive women with children who were HIV positive. The work was emotional but hugely rewarding and these women were living with uncertainty as treatment options were just improving. As the options to prevent the vertical transmission of HIV came on board during the late 1990s, I was pleased with this development, however these mothers could not be cured so would remain HIV positive which is where the idea of this research came from.*

*I currently work as a nurse lecturer in an Irish university and my decision to do a doctorate was to further my academic career. I embarked on this journey with some trepidation; could I care for my children and continue to work and do my research? However, my struggles were insignificant, when I met the women who shared their personal stories with me about mothering with HIV and now respectfully I am the messenger of their narratives. I thank them sincerely for sharing their experiences with me as part of this study.*

*I want to acknowledge the guidance and support of my two supervisors Dr Alan Buckingham and Professor Corinne Squire who have patiently steered me through this long journey. In addition, my colleagues on the professional doctorate programme at Bath and my academic colleagues, and friends especially Briege Casey in DCU, who all helped in different ways while on this journey. To my non-academic friends, who never really understood why and what I was doing thanks for the nights out/shopping trips to distract me from my seemingly never-ending task. I dedicate this thesis to my parents John and Phil who sadly are no longer with us, but both understood the importance of determination to achieve one's goals. Finally, I want to thank three special people: my husband Roger and our two children Michael and Orla who love me whether I am a nurse or a doctor.*

## **Abstract**

Mothers living with HIV (MLH) are the focus of this narrative study. HIV is increasingly seen as a chronic illness because of medical advances in its treatment. Much research with HIV positive mothers is situated within the dominant biomedical discourse focusing more on outcome rather than experience and, while valuable, it fails to provide insight into their subjective experiences. In Ireland, women represent a third of the newly diagnosed HIV population (O'Donnell, Moran and Igoe 2013), many of whom have children, and migrant African-origin women represent a significant percentage of these new diagnoses. However, no research has examined contemporary maternal HIV experiences within an Irish context. This is an important fact considering the changing nature of HIV and that most HIV positive women are prescribed Highly active antiretroviral treatment (HAART) during their pregnancies and so give birth to HIV negative babies. This study explores the HIV maternal experience as the psychosocial impact of being HIV positive persists even though it is increasingly seen as a chronic illness. The original contribution to knowledge of this thesis is to provide insight into the experiences of mothers living with HIV in Ireland.

My study involved adopting a narrative approach to interviewing a purposive sample of eleven HIV positive mothers living in Ireland who were at different points on the motherhood trajectory, and were from both high and low HIV prevalence countries. The analysis of this study's narratives drew on a combination of theoretical perspectives including HIV stigma frameworks (Campbell et al., 2007, Herek 2002), social capital theory (Putnam 1995), medicalisation and HIV normalisation.

The interviews reveal the centrality of being a mother to the study participants and how being HIV positive affects mothering. Being an HIV positive mother means protecting children from HIV from the moment of diagnosis, during and after pregnancy; minimising the impact of HIV in everyday life; having an awareness of the persuasiveness of HIV stigma; and managing HIV disclosure. Peer support was a significant factor for these mothers and all were members of an HIV support organisation in Dublin. Linking the findings of this study to wider theoretical literature allows for a greater understanding of the lives of HIV positive mothers in the HIV normalisation era and accentuates the multidimensional impact of maternal HIV infection.

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## **Abbreviations**

**AIDS** Acquired Immune deficiency syndrome.

**BHIVA** British HIV Association.

**CD4** are a type of white blood cells (which increase in the presence of infection) and a CD4 count can indicate the stages of HIV infection.

**HIV** Human immune deficiency virus.

**MLH** Mothers living with HIV.

**MTCT** Mother to child transmission (either during pregnancy, delivery or in the post-natal period).

**NSHPC** National Study of HIV in Pregnancy and Childhood for UK and Ireland.

**UNAIDS** is the joint United Nations programme on HIV/AIDS.

## Glossary of Terms

**Antenatal testing** for HIV involves a blood test for HIV antibodies at the first booking appointment usually when a woman is approximately three months pregnant.

**Antiretrovirals** medications used to treat HIV. There are several classes of antiretrovirals, which work by disturbing the HIV lifecycle to suppress the virus replication process. Usually at least three antiretrovirals are prescribed together.

**HAART** Highly active antiretroviral treatment is the term that refers to the prescribing of a combination of antiretrovirals to treat HIV or prevent vertical transmission.

**Vertical transmission** refers to the transmission of HIV from mother to her baby during pregnancy.

**Viral load** is the amount of HIV circulating in the blood, it indicates viral activity and can indicate disease progression.

*EVERYONE HAS EXPERIENCED A MOTHER, BUT ONLY  
MOTHERS HAVE EXPERIENCED MOTHERHOOD“*

*CAROL LONG (2009 P. 72)*



## ***Chapter One: Introduction***

### **1.1 HIV/AIDS**

HIV/AIDS remains a high priority public health problem. The 2013 UNAIDS report on HIV worldwide estimates that 35.3 million people were living with HIV in 2012 (UNAIDS 2013). Due to the success of biomedical advances in HIV treatment and prevention strategies, the numbers of people acquiring HIV is declining worldwide (UNAIDS 2013). Accordingly, a reduction in HIV related mortality is increasingly evident (UNAIDS 2013). Since 1996, the use of Highly Active Antiretroviral Therapy (HAART) has had a dramatic effect on HIV disease progression and on prevention of vertical transmission (VT) which is the transfer of the virus from mother to baby during pregnancy or after birth. In the fourth decade of the HIV epidemic, life expectancy of those living with HIV is now no different to that of the general population. As life expectancy has changed, it is increasingly accepted that HIV is now a chronic condition, even though the psychological and social impact of HIV remains. HIV as a research topic, has received a lot of attention since the epidemic began and, as a result of such research, treatment options have improved significantly for those living with the virus. Mykhalovskiy and Rosengarten (2009) have suggested that the dominance of quantitative and medical evidence-based HIV research has contributed to a lack of consideration of the contemporary psychosocial issues of life with HIV. Flowers (2010) highlights that HIV positive individuals have unique psychosocial struggles, despite the welcome reduction in HIV morbidity and mortality.

### **1.2 HIV/AIDS in Ireland**

The exact numbers of people living with HIV in Ireland are not known. An Irish survey conducted in 2012 reported that over three thousand HIV positive individuals were accessing care in the designated HIV care centres (Tuite et al. 2012). In Ireland, by the end of 2012, six-thousand and twenty- nine people had been diagnosed HIV positive (O'Donnell, Moran, and Igoe 2013) since the commencement of testing in the late 1980s. The annual numbers of newly diagnosed individuals in Ireland has been decreasing since 2008, although an increase of seven per cent was noted in the 2012 figures compared to the 2011 figures (O'Donnell, Moran, and Igoe 2013). In 2012, forty-nine per cent (n=341) of newly diagnosed individuals in Ireland were men who have sex with men. Nearly half, forty-eight per cent, of newly diagnosed individuals

were born abroad with sixty-three per cent of newly diagnosed heterosexuals (n=130) coming from countries in which over one per cent of the population are HIV positive (O'Donnell, Moran and Igoe, 2013).

The most recent Irish figures reveal that in 2012 women represented twenty- eight per cent (n= 341) of newly diagnosed individuals, with the highest representation in women aged between thirty to thirty-four years old (ibid). Since 1990, one- thousand- four- hundred- and three babies have been born to HIV positive mothers living in Ireland (National Study of HIV in Pregnancy and Childhood NSHPC, 2013).

A small number of studies have explored the maternal HIV experience in the USA, Australia, South Africa and UK, largely emphasising the importance of mothering to these women (Long 2009, Sanders 2009, 2008, Brandt 2008, Sandelowski and Barosso 2003a, 2003b). Two UK-based studies have partially explored the mothering experiences of HIV positive women (Wilson, 2007, Doyal and Anderson 2005, Anderson and Doyal, 2004) and have relevance to this study due to geographical closeness and a similar HIV population profile. Although mothering was not the primary focus of the UK studies, issues concerning mothering experiences and challenges emerged during data collection.

### **1.3 Rationale for research**

The need for an Irish study of mothers living with HIV arises because most newly diagnosed women are of childbearing age (O'Donnell, Moran and Igoe 2013) and the predominant discourses with HIV positive mothers is associated with the prevention of vertical transmission of HIV during pregnancy. Little is known about current HIV positive women's mothering experiences after pregnancy. By exploring how these women deal with being a mother while living with a stigmatising condition, this study will offer an understanding of how being HIV positive impacts on their mothering. HIV is not just a health issue as it influences all aspects of a mother's life and the consequences of this diagnosis are different for each mother. This original study will explore, from the women's point-of- view, how being HIV positive impacts on mothering.

## **1.4 Research question and objectives**

The research question was posed as: “What are the experiences of mothers living with HIV in Ireland?”

The study objectives were:

- To understand the subjective experiences of mothering while HIV positive, including pregnancy, through the adoption of a narrative approach.
- To give participants an opportunity to narrate their HIV experience.
- To explore the psychosocial impact of the maternal HIV experience in the HIV normalisation era.
- To establish how the lives of HIV positive mothers can be understood theoretically in relation to existing literature including social capital theory, feminist mothering theory and theories of HIV stigmatisation, disclosure and normalisation.
- To gain understanding as to how these mothers construct meaning with a view to informing those who provide care/support for them, as child rearing may take priority over the mother’s own personal needs.

## **1.5 Thesis structure**

This thesis comprises six Chapters, which describe this research study. Chapter Two presents a literature review on mothering and HIV. The review focuses on key research relating to the psychosocial impact of HIV on mothers and appraises previous studies with HIV positive women and mothers; it also identifies pertinent issues that affect mothers living with HIV and that their lives are under-researched. Chapter Three describes and justifies the selection of a narrative approach to the study and explains the study data collection and analysis process.

Chapter Four presents the study findings. I use key narrative threads from the interviews to illustrate how this study’s participants make sense of their experiences as HIV positive mothers. Chapter Five presents a discussion of the findings while relating them to previous studies and highlights new insights that emerge from this study. Chapter Six reviews the thesis and its findings, and makes recommendations for future research.

## ***Chapter Two: Literature Review***

### ***2.1 Introduction***

This Chapter presents a review of the existing theoretical and empirical literature concerning the experiences of mothering while HIV positive. This examination will demonstrate the need for further research in this area and will outline the areas where knowledge and understanding are lacking. The Chapter opens with an outline of HIV as it applies to women in Ireland to contextualise the study, provides a summary of contemporary HIV treatment, and presents some of the current debates in the HIV arena as they apply to mothers. This is followed by an analysis of the concept of mothering and how being ill impacts on mothering. The next part of the review offers an appraisal of previous published research investigating mothering within the context of HIV infection. This provides a foundation for understanding the experiences of HIV positive women and highlights why further research on the contemporary maternal HIV experience is warranted and timely.

### ***2.2 Section one: mothering and HIV***

This section presents an overview of the issues pertaining to HIV positive women in Ireland and identifies the key issues in HIV management with women. It examines mothering discourses with particular emphasis on feminist mothering theory. It explores previous research with mothers who are ill as well as studies with mothers living with HIV.

#### ***2.2.1 HIV and women: the Irish figures***

The largest group of newly diagnosed women in Ireland are of childbearing age and in the most recent figures twenty-three per cent (n=341) were pregnant when diagnosed (O'Donnell, Moran and Igoe 2013). Antenatal testing for HIV began in Ireland in 1999 (Coulter-Smith et al. 2010) to identify women who are HIV positive so that they can have antiretroviral treatment during their pregnancies to prevent vertical transmission of HIV to their babies. Between 2002 and 2010 in Ireland due to antenatal testing one- thousand-one -hundred and thirty -three HIV positive women were identified, with four- hundred and forty- six of them not previously



known to be HIV positive (O'Donnell and O'Hara 2012). Ireland, like many western countries, has had a low rate of vertical transmission since the introduction of HAART. In the early years of the HIV epidemic, many HIV positive mothers were known intravenous drug users (Coulter-Smith et al. 2010). Despite the reduction in numbers of diagnoses of drug using women in Ireland, some newly diagnosed women may be partners of drug users. Moreover, in Ireland, the introduction of antenatal HIV testing occurred when there was an increase in immigration from Sub-Saharan Africa and Eastern Europe, which has had a significant impact on the Irish newly diagnosed HIV figures (Coulter-Smith et al. 2010). More recently, non-drug using mothers from Sub-Saharan Africa are increasingly evident in the annual Irish HIV figures due to antenatal testing (O'Donnell, Moran and Igoe, 2013).

### **2.2.2 Contemporary HIV management and mothers**

The medical treatment of HIV changed with the introduction of Highly Active Antiretroviral Treatment (HAART) in the mid-1990s. This development altered the prognosis for HIV positive individuals (Davis, Frankis and Flowers, 2006) and many now consider HIV as a treatable (McDonald 2011, McDonald and Kirkman 2011, Cibulka 2007), long-term condition (Bravo et al. 2010). HAART involves the prescribing of multiple antiretroviral drugs that focus on different aspects of viral replication, in order to hinder HIV assault on the immune system. HAART involves complex drug regimens where adherence is of upmost importance to ensure maximum effectiveness (Hubbard 2006) and those taking it may experience unpleasant side effects.

For discussion purposes, three key periods identify the HIV epidemic. The pre-HAART era was when treatment options were limited and lasted from the 1980s until the mid-1990s. The HAART era is the time since the introduction of HAART and the subsequent improved HIV morbidity and mortality. Most recently, there is evidence of a new phase that promotes HIV normalisation. HIV normalisation involves embracing the biomedical technological advances of HIV management and considering it a treatable chronic condition (Flowers 2010, Squire 2010), and is strongly influenced by medical expertise and supported by epidemiological data. This medical construction of HIV, while central to its understanding, has contributed to a sidelining of the psychosocial issues.

The concept of medicalisation originated from the work of Irving Zola and Ivan Illich in the 1970s (Shipman Gunson 2010). According to Conrad, Mackie and Mehrotra (2010) medicalisation is:

The process by which non-medical problems become defined and treated as medical problems, usually as illnesses or disorders (p.1, 943).

Michel Foucault's writings about the power of medicine have influenced the social debate about medicine, health, and illness. He argues that medicine is an institution of power that labels bodies as deviant or not and considers the body as the ultimate site of political and ideological control, surveillance and regulation (Lupton 2007). Foucault suggests that medicalisation sees patients as passive participants who are encouraged to adopt the clinical way of thinking and articulating medical complaints (Lupton 1997 cited in Shipman Gunson, 2010). Medicine is a powerful force within society and medicalisation is evident across many spectrums of health, including addiction, sleep disorders, and menopause (Conrad, Mackie and Mehrotra 2010). Building on Foucault's work, Rose (2007) describes medicalisation as the extension of medical authority beyond its remit and suggests that it has become "a cliché of critical social analysis" (p. 700, 2007) and argues for moving beyond it because medicalisation has become all-encompassing. Shipman Gunson (2010) proposes that recently there have been efforts to incorporate the patient perspective into medicalisation and develop it from its current narrow perspective. However, concern remains that medicalisation has become too dominant (Rose 2007) and this is certainly evident in the HIV field, as its treatment can be said to be highly 'medicalised'. Lupton (2007) notes that many public health initiatives in the early years of the HIV epidemic focused on controlling and containing the spread of the disease. Flowers (2010) argues that the current dominance of the medical construction of HIV infection is founded on the assumption that the health of HIV positive individuals can be assessed primarily through the use of two specific blood tests usually done at three to six monthly intervals. An HIV viral load test measures the amount of active HIV in the blood; while the CD4 count identifies the amount of white blood cells (which increase in the presence of infection) and can indicate the stages of HIV infection. A low CD4 count will indicate that an individual is immune-suppressed whereas a low viral load indicates that the HIV is not currently active, usually due to HAART. Flowers (2010) asserts that this biomedical account of HIV can overlook the subjective experience of those who are living with it.

In terms of medical well-being and the treatment of HIV, both the HIV viral load and the CD4 count are of central importance to the clinician, as these results influence treatment decisions. It follows from this that the understanding of people living with HIV tends to be highly medicalised, with little attention paid to the social and psychological impact of living with HIV. The intense research in the first 20 years of the HIV epidemic has resulted in it being viewed as a more treatable condition. By embracing this treatment as an HIV prevention paradigm, the dominance of biomedical technological advances has brought exciting possibilities for those who are HIV positive. There is no doubt that as HIV has become more treatable, long-term survivors of HIV are now facing health challenges as a result of ageing; for example, cardiac disease develops earlier in HIV positive individuals (Owen and Catalan, 2012). Additionally, the use of HAART treatment as an HIV prevention strategy is gaining momentum due to its effectiveness in reducing the amount of virus in the blood to an undetectable level, in turn reducing infectiousness (Persson 2012), which would have been inconceivable earlier in the HIV epidemic. Flowers (2010) posits that the assumption that HIV is a treatable chronic illness underpins the normalisation of HIV and presumes that related stigma will reduce as the condition becomes more treatable and mainstream. However, evidence to the contrary exists and there are a number of criticisms against the normalisation of HIV.

Persson (2012) argues that caution is necessary in the framing of HIV within this discourse of normalisation, as it appears to minimise the psychosocial challenges of being HIV positive. While the medical advances have been highly significant, the psychological impact on those with HIV is less obvious. Squire (2010) further argues that the medicalisation of HIV has resulted in an overshadowing of the psychosocial issues associated with living with the virus. Importantly, the notion that HIV remains an infectious, stigmatised condition persists in many societies. Indeed many individuals with HIV struggle with the unique psychological aspects of being HIV positive that normalisation cannot eradicate. In support of this, Bravo and colleagues (et al. 2010) further highlight that disclosure, adherence to medications, and negotiation of sexual relations remain challenging for HIV infected individuals.

Davis and Squire (2010) claim that a weakness of HIV normalisation lies in the lack of consideration given to the emotional impact of everyday living with the virus. Supporting this, Bravo and colleagues (et al. 2010) argue that a major drawback of the normalisation of HIV is that the physical challenges and the psychosocial impact of HIV remain even when the blood results are stable. In her paper on HIV naturalisation, Squire (2010) challenges normalisation and argues that HIV is different from other chronic illnesses. Firstly, HIV is associated with

sexual promiscuity and drug use. Accordingly, many people with HIV do not tell family and friends for fear of judgement or discrimination. HIV's stigma and physical difficulties continue to affect individuals' relationships, work, and future. Secondly, there is still no cure for HIV, a fatal condition, despite the treatment advances that involve complex HAART drug regimens and can result in side effects and drug resistance (Squire 2010).

HIV is unique in that the potential to infect others continues throughout an individual's lifespan. Unlike other chronic illnesses, HIV has disproportionately affected certain marginalised groups, particularly gay men and those from Sub-Saharan Africa. Moreover, many of those living with HIV have lost friends, children, and partners to HIV/AIDS and the manner in which they deal with being HIV positive is intricately bound to these previous experiences. Mykhalovskiy and Rosengarten (2009) further draw attention to the lack of consideration of the contemporary social understandings of life with HIV and suggest that this is due to the dominance of evidence-based quantitative HIV medical research. Flowers (2010) points out that since the advent of HAART, research on the social aspects of living with HIV appears increasingly secondary to biomedical HIV prevention research; however, living with HIV may still affect psychosocial wellbeing (Bravo et al. 2010). Indeed, recent research has shown that the psychological burden of HIV remains (Bernays 2011, Flowers 2010). Researchers who have explored the individual social and psychosocial aspects of life with HIV in the HAART era emphasise the on-going difficulties faced by those living with HIV, for example, managing stigma, and disclosure decisions (Bravo et al. 2010, Davis, Frankis and Flowers 2006, Flowers et al. 2006, Anderson and Doyal 2004, Doyal and Anderson 2005).

For HIV positive women, becoming pregnant brings with it the possibility of infecting their baby: this can occur in utero, during labour, delivery or through breastfeeding. However, the use of HAART has reduced vertical transmission of the virus during pregnancy (Craft et al. 2007) and so positively influenced the reproductive decisions of women with HIV (Cliffe et al. 2011). If an HIV positive pregnant woman takes HAART during her pregnancy, the chances of infecting her baby are low as currently the mother to child transmission (MTCT) rate is less than 1% in the Western world (NSHPC 2013). The majority of known HIV positive pregnant women in England and Ireland take HAART during pregnancy (NSHPC 2013).

Importantly, becoming a mother is now a realistic option for many HIV positive women due to the availability of HAART, the reduced risk to the mother's health and low risk of sero-positivity in the child (Kelly, Alderice, and Lohan 2009). Recent evidence suggests that the number of HIV

positive women experiencing repeat pregnancies is on the increase in the UK and Ireland (French et al. 2012). While HAART is widely available in Western Europe/USA, universal access still has to be realised across the world. The most recent UNAIDS strategy is aiming for the elimination of vertical transmission and the provision of worldwide access to HAART by 2015 (UNAIDS 2013).

Remarkably, few studies have taken into account the maternal experience of living with HIV. HIV affects men and women differently (Walsh et al. 2012) and having children will have a major impact on their experience of HIV disease (Anderson and Doyal 2004). Taking into account the impact of an HIV diagnosis on mothers, the notion of intersectionality, which is strongly influenced by feminism, can be useful to explore the multiple dimensions of the HIV experience (Doyal 2009). Intersectionality seeks to acknowledge the multiple gender dimensions of maternal HIV experiences and how power and exclusion shape their lives (Campbell and Gibbs 2009). For HIV positive mothers, the intersection occurs through multiple representations that invoke to shape their individual identities and experiences. Intersectionality can support an exploration of the multiple unique dimensions of the maternal HIV experience, including stigma and discrimination. Current research effort focusing mainly on the prevention of VT of HIV during pregnancy has resulted in a lack of attention to the psychosocial experiences of mothers living with HIV. As discussed earlier in this Chapter HAART and HIV survivorship is well established, however there is a gap in knowledge about the real life experiences of MLH in this HAART treatment era. To this end, this thesis sets out to explore Irish based mothers' experiences of living with HIV in this post HAART era. It adopts a critical approach to HIV normalisation as it pertains to mothers living with HIV to argue that the normalisation of HIV is still an aspiration (Squire 2010). Having considered challenges within the contemporary HIV field as they apply to women and mothers, the section to follow considers mothering as a social construct and a feminist concept; how being ill affects mothers; and the significance of mothering as it relates to HIV positive women.

### **2.2.3 Mothering**

Warnes and Daiches (2011) assert, "Motherhood is constructed as a positive experience" (p.110) and these discourses tend to support the good mother stereotype, showing little regard for subjective mothering experiences. Myths of perfect motherhood persist, despite the fact that the reality is very different for many mothers (Miller 2007, 2005) as a diversity of

mothering experiences exist (Phoenix 2011). Women's roles as child rearers, wives, and family nurturers are enshrined as the ideal in the Irish Constitution (Inglis 1998 cited in Woods 2007). The Irish Constitution links the place of women in society to motherhood. This is evidenced in Article 41. 2 of Bunreacht na hÉireann (official title of Irish Constitution):

In particular, the State recognises that by her life within the home, woman gives to the State a support without which the common good cannot be achieved. The State shall, therefore, endeavour to ensure that mothers shall not be obliged by economic necessity to engage in labour to the neglect of their duties (Bunreacht na hÉireann 1937).

Miller (2005) distinguishes between motherhood and mothering, proposing that motherhood is the context in which mothering takes place and the experiences mothers have while caring for their children is mothering. Mothering includes being pregnant, childbirth, and parenting and being a mother can give a woman a sense of fulfilment and for many women having children is a source of identity, pride and achievement (Walzer 2007 cited in Vallido et al. 2010). Research with mothers commonly focuses on issues relating to their children being ill or having difficulties with schooling. Shelton and Johnson (2006) further argue that most studies with mothers have tended to focus on pregnancy and the transition to motherhood and portray the experience as a largely positive experience. More recently, other researchers have explored the subjective experiences of mothers (Long 2009, Miller 2007, 2005, Woods 2007) rather than just focusing on child rearing.

However, when real experiences of mothering do not fit within the ideal it can be problematic. Much qualitative research explores experience which Scott (1991) defines as "an interpretation and something that needs to be interpreted" (p.797). This definition suggests that experiences are a way to describe what happens in everyday life, how events are made sense of and understood. Mothering experiences are personal and dependant on social, cultural, and environmental factors and not homogenous. In the medical field, 'good and bad' motherhood and natural childbirth discourses about mothering dominate in Western society (Miller 2007). Warnes and Daiches (2011) challenge the notion that all mothers will bond with their children and find being a mother satisfying. They argue this view influences the expectations women have before they become mothers (Warnes and Daiches, 2011). This gap between idealised expectations and the lived reality of mothering is increasingly evident in feminist orientated research (O'Reilly 2008, Middleton 2006). Indeed, many mothers

experience societal disapproval because they do not fit with an idealised view of motherhood due to illness, disability or drug use.

O'Reilly (2008) argues that age, race and sexuality do not determine a woman's capacity to mother and that mothering is more than childrearing. As such, feminist mothering involves four conditions Agency, Autonomy, Authenticity, and Authority (Middleton 2006) which collectively contribute to 'empowered' mothers. Feminist mothering researchers challenge patriarchal concepts of motherhood by identifying and investigating feminist maternal practices as mechanisms for the empowerment of women and social change (Hunter 2009, O'Reilly 2008). It also aims to highlight counter narratives of mothering within our paternalistic society (O'Reilly 2008). Feminist mothering research argues that both the children and mother benefit when the mother lives her life from a position of autonomy; a mother can meet her own needs through work or hobbies and still care for her children. However, criticism from Middleton (2006) argues that most research drawing on feminist mothering has explored the mothering of educated, middle class women and that there are few examples of feminist mothering with mothers who are from lower socioeconomic groups or are part of marginalised groups, for example those addicted to drugs or asylum-seekers.

Middleton (2006) proposes that mothers in challenging situations have been given limited consideration by feminist researchers and she questions the usefulness of feminist mothering theory in relation to mothers who are dealing with multiple life issues, including illnesses like HIV, living in poverty and being a migrant. However, she advocates that care providers should consider feminist mothering conditions when planning and implementing care for mothers if they are not in a position to make changes themselves (Middleton 2006). Women-centred research can present a very different picture of mothering, particularly for women dealing with competing challenges, when used to inform policy and practice.

The notion of 'mothering on the margins' (Craig and O'Dell 2011, Phoenix 2011) recognises that less than 'ideal' mothering situations, in conventional terms, are becoming more common and accepted by society. 'Mothering on the margins' develops the feminist mothering stance by questioning the dominant social and cultural expectations of motherhood and questions the belief that certain types of mothers are better suited to rear children than others. Adopting the 'mothering on the margins' perspective allows for exploration of maternal experiences of women considered by some to be on the edge of society. These include lesbian mothers, mothers living with addictions or in prison. Furthermore, 'mothering on the margins'

reinforces the importance of social context for shaping the mothering experiences of a woman and can relate to HIV positive mothers. Barnes and Murphy (2009) argue that in society the perception remains that HIV positive women are unsuitable to be mothers. This negative perception may be a result of the continued association of HIV with illicit drug use and sexual promiscuity, reinforcing the continued stigmatisation of those living with HIV (Squire 2010). This perspective of 'mothering on the margins' will inform this study.

#### **2.2.4 Mothering when ill**

Few studies have considered how long-term health conditions affect women with children. Fisher and O' Connor (2012) and Elmberger and colleagues (2008) examined the experiences of mothers with cancer. These studies found that mothers dealing with cancer were concerned with protecting their children from the reality of the illness, while simultaneously trying to be honest with them about their own health. Additionally, mothers reported that they felt like failures because they might not live long enough to see their children to adulthood (Elmberger et al. 2008). Fisher and O'Connor (2012) highlight that health professionals failed to acknowledge how being mothers complicated their illness experience. Furthermore, a recent review by Vallido and colleagues (2010) considers the impact of chronic illness on mothers and reports that mothers struggle with their primary care giving role while trying to protect their children from the various effects of illness.

While these studies focused on mothering and illness generally, their findings are relevant to mothers living with HIV. Despite the fact that many women with HIV may have periods when they are symptom free and well, the findings from these studies suggest long-term illness does impact on mothers (Fisher and O'Connor 2012, Vallido et al. 2010, Elmberger et al. 2008). Mothers who are ill have to manage, for example, fatigue and hospitalisation as well as deal with side effects of medication while caring for their children. Vallido and colleagues (et al. 2010) recently confirmed that mothers who are dealing with chronic illnesses like arthritis, mental illness or cancer consider themselves as mothers first and then as patients; therefore, care giving/parenting may take priority over mothers' own healthcare needs and this should be considered when exploring the lives of HIV positive mothers.



### 2.2.5 Mothering when HIV positive

While HIV positive mothers face many similar challenges to mothers who have other chronic illnesses, there are also unique factors to mothering with HIV. Issues that are particular to MLH may include planning their pregnancy and taking into account conception options depending on the HIV status of their partner (Cibulka 2007), and they may have to deal with being diagnosed when pregnant (Kelly et al. 2012, Long 2009, 2006). In addition, research suggests that the process of preventing MTCT (mother to child transmission) when pregnant can be emotionally taxing (Kelly et al. 2012, Kelly, Alderice and Lohan 2009). Another concern for HIV positive mothers is establishing the HIV status of their new-born babies (Shannon and Lee 2007). Walulu and Gill (2011, Walulu 2007) found that HIV positive mothers try to balance their own health needs with those of their children. Hunter (2009) further suggests that mothers living with HIV tend to prioritise their children's needs.

A number of studies explored the lives of HIV positive women in the pre and early HAART era i.e. mid 1980s to early 2000s, when HIV was life-limiting. In many of these studies, mothering was not the primary focus; however, mothering experiences and challenges emerged during data collection. Previous research examining the subjective experiences of HIV positive women in the USA has explored fertility intentions (Craft et al. 2007, Cibulka 2007). Ndirangu and Evans (2009) and Doyal and Anderson (2005) examined the challenges facing African migrant women<sup>1</sup> with HIV living in the UK, while Sanders (2009, 2008) and Wilson (2007) explored the experiences of HIV positive women with drug using histories. Mothers were well represented in these qualitative studies and, unsurprisingly, issues relating to mothering were discussed. Primary among the mothering issues in these studies were disclosure to children, avoiding stigma and being around for their children's milestones.

There has been little recent research on the subjective life experiences of HIV positive mothers as their children get older and as they deal with the long-term impact of the disease. Research conducted in the US considered the experiences of HIV positive women, and being a mother emerged as a significant theme across many studies. Sandelowski and Barroso (2003a, 2003b) conducted an important metasynthesis of fifty-six US based qualitative studies with HIV positive women, focusing on studies conducted during the mid to late 1990s in the USA when

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<sup>1</sup> For the purpose of this thesis discussion, the term migrant women refers to African women who are either seeking asylum or have refugee status in Ireland.

the use of HAART had commenced but was not established. Most of the studies examined did not set out to explore mothering experiences; they emerged as significant during data collection, thereby highlighting the centrality of mothering to HIV positive women. Sandelowski and Barroso (2003b) reported, "Motherhood both intensified and mitigated the negative physical and social effects of HIV infection "(p. 470).

Sandelowski and Barroso (2003b) described that for many HIV positive mothers, having children to care for provided them with their main reason to live and motivated them to care for themselves. Indeed, mothers described their children as sources of support to them and said that being a mother cushioned the negative effects of living with HIV. Sandelowski and Barroso (2003a) also found that care providers fail to acknowledge the impact that being a mother has on women with HIV and maintain that care for these mothers should maximise the benefits that being a mother brings to women, and minimise the burden. These deliberations contribute significantly to the literature on mothering with HIV. However, the relevance of Sandelowski and Barroso's research to the contemporary care of HIV positive mothers is unclear, as most of the studies examined predate the widespread use of HAART.

Mothering while HIV positive was the focus of Ingram and Hutchinson's (2000, 1999) grounded theory study. Eighteen women with HIV disease were interviewed and the results indicated that mothers who are HIV positive practised 'defensive mothering' as their way of coping with the illness. 'Defensive mothering' involves preventing further spread of HIV to their children, preparing their children for a future life without them and trying to manage negative thoughts about their lives (Ingram and Hutchinson 2000, Ingram and Hutchinson 1999). These findings provide a worthwhile perspective on the maternal HIV experience within the USA context when HIV was still a life threatening condition. The concept of 'defensive mothering', describing how mothers manage the challenges of being HIV positive, may still have relevance for MLH in the current normalisation era because, as argued earlier in this Chapter, the burden of mothering while HIV positive still exists despite the success of HAART.

In her phenomenological study with HIV positive mothers in the early years of HAART, Nelms (2005) presented an alternative view of mothering while HIV positive and revealed that participants have a consistent feeling of burden attributed to the psychological impact of the condition. This study highlights the psychosocial effects of mothering on women who are HIV positive including perceived stigma, keeping their HIV a secret and the future dilemma of maternal disclosure of their HIV status. Nelms (2005) reported that these women felt

overwhelmed by their circumstances, struggled with self-doubt, and had concerns for the future. Mothers in this study also spoke about wanting to be around for their children's milestones, like going to college and becoming grandmothers (Nelms 2005).

Similarly, Wilson's (2007) study of HIV positive women living in Scotland (many of whom were ex-drug users), found that they too wanted to be around until their children reached adulthood and were concerned that their illness might jeopardise their plans. This study drew on biographical disruption theory to explore their lives. According to Bury (2001, 1991), biographical disruption is a way to consider the impact of chronic illness on an individual's life plans. Her respondents wanted to be 'good mothers', despite the fact they were living with a stigmatised condition and had a drug misuse history. Additionally, they tried to protect their children from the effects of the illness (Wilson 2007). This study's timing is significant as data collection was during the late 1990s after the widespread introduction of HAART, but it was only published in 2007. This delay limits the value of the study to the contemporary HIV picture, now that increased longevity is possible for those who are HIV positive. Data from Barnes and Murphy's (2009) follow-up post-HAART study with female long-term survivors of HIV also highlighted the importance of having children. They reported that participants, who had previously viewed their HIV diagnosis to be a death sentence, subsequently considered having children to be 'life sustaining' (Barnes and Murphy 2009 p. 133).

However, these findings may have relevance to the current study, as more recently Walulu and Gill's (2011) post-HAART research reported that HIV positive mothers were concerned that they would not be around to see their children grow up. As discussed, mothering experiences are influenced by many factors and MLH have to deal with many challenges, even if strategies to prevent VT are effective; most known HIV positive women now give birth to HIV negative children (NSHPC 2013).

## **2.3 Section two: Research with mothers living with HIV**

This section presents studies that consider women's HIV diagnosis experiences, how HIV positive women manage reproductive health concerns, the challenges faced by migrant MLH and the psychosocial aspects of HIV as they apply to HIV positive women and mothers.

### **2.3.1 Receiving an HIV Diagnosis**

The introduction of antenatal HIV screening was a way to detect, identify and treat HIV positive pregnant women in order to prevent vertical transmission of HIV (Kelly, Alderdice, and Lohan 2009) and commenced in Ireland in 1999 (Coulter-Smith et al. 2010, Foreman and Hawthorne 2007). There is no doubt that an HIV diagnosis when pregnant has a significant impact on affected women, as the issue of avoiding vertical transmission takes priority (Kelly et al. 2012, Kelly, Alderdice, and Lohan 2009). However, few studies have considered the subjective experiences of newly diagnosed pregnant women. One exception is Long's South African study, which highlighted the complexity of the transition to mothering following a recent HIV diagnosis (2009, 2006). Long reports that participants maintain two conflicting identities; they are creating new life while also dealing with the shock of a recent HIV diagnosis and the potential judgement that comes with that news. South Africa is currently one of the countries with the largest HIV affected population in the world (UNAIDS 2013) and heterosexual migrants from Sub-Saharan and South Africa are the largest group of newly diagnosed people in Ireland (O'Donnell, Moran and Igoe 2013). Long's research can resonate with this study's population which is mothers living with HIV in Ireland, a group in Irish society from which this study draws some of its purposive sample and of which a significant proportion are from Sub-Saharan Africa.

When pregnancy coincides with diagnosis, the emphasis tends to be on the medical aspect of care, focussing on the prevention of mother to child transmission rather than on the mother's wellbeing (Kelly, Alderdice, and Lohan 2009). Kelly and colleagues (2012) reported on the experiences of four women diagnosed unexpectedly when pregnant in Northern Ireland. This exploration, which was part of a larger study, revealed the impact of an HIV diagnosis when pregnant, as the focus of these newly diagnosed women shifted from looking forward to the birth of their baby to the prevention of vertical transmission. Their paper drew on Becker's model of continuity following disruption (Becker 1997, cited in Kelly et al. 2012), which attempts to explain how people deal with disruption through assessing the difference between

planned life and actual life experiences. In this instance, it highlighted that the timing was noteworthy as the diagnosis had a significant impact on the women's pregnancy experiences.

Studies in the HAART era have explored how women deal with an HIV diagnosis and even though it is no longer considered life threatening, an HIV diagnosis can be overwhelming (Stevens and Hildebrandt 2006), life-changing and can bring uncertainty (Walsh et al. 2012, Walulu and Gill, 2011, McDonald 2011, McDonald and Kirkman 2011, McDonald 2008, Walulu 2007). Crossley's (2000) research, prior to the widespread introduction of HAART, highlighted that one of the psychological impacts of the diagnosis was an uncertain future for individuals. Walsh and colleagues (2012) posit that a woman's reaction to an HIV diagnosis also relates to how prepared she is for a positive result. This research highlights that many women who perceive themselves as not at risk are shocked when diagnosed (Walsh et al. 2012), which may contribute to how they deal with the news. McDonald's (2008) Australian study explored the impact of an HIV diagnosis on women's mothering intentions; she found that on initial HIV diagnosis, many women did not intend to have children because of the possibility of infecting their unborn child. However, many of these women did become mothers later, while some would not consider having children despite the advances in HIV treatment (McDonald 2008).

Other research has considered how mothers deal with an HIV diagnosis. Walulu and Gills study (2011, 2007) found that upon diagnosis mothers have two main concerns; they worry about the possibility that they may have infected their children or spouse, and they are concerned as to whether they will live long enough to raise their children. The management of maternal disclosure to children is also an immediate concern for many mothers when diagnosed (Hawk 2007). For some mothers becoming HIV positive can be a motivator to change. According to Pittiglio and Hough (2009), after an HIV diagnosis mothers in their study:

... Developed new attitudes toward life, more positive behaviours and, in most cases, began to live life differently (p.190).

Having considered the impact of an HIV diagnosis, the section to follow evaluates previous psychosocial research with HIV positive women and mothers.

### **2.3.2 Reproductive challenges for HIV positive women**

The reproductive decisions facing HIV positive women are an important theme in the HIV literature. Previous studies have argued that being HIV positive may not affect fertility, but it

does influence reproductive/pregnancy decision-making (Craft et al. 2007, Kirshenbaum et al. 2004). French and colleagues (2012) report that half of pregnancies of known HIV positive women are unplanned, which concurs with figures for non-affected women, which suggests their contraception needs are not being met. Certainly, the decision to have a child is complex for a woman with HIV, as it involves the possibility of bearing an HIV infected child while dealing with a serious and stigmatised illness. Reichert (2010) draws attention to the fact that pregnant HIV positive women and mothers must incorporate HIV into their identity and negotiate prevailing maternal ideologies, while dealing with the demands of their illness.

D'Arcy and colleagues emphasise that becoming a mother is important for many women (D'Arcy et al. 2012) and for mothers who are living with an illness their desire to have children is not lessened (Vallido et al. 2010). A recent survey of UK based HIV positive women's fertility intentions revealed that forty-five per cent (n=450) of participants did not feel the diagnosis had affected their plans to have children (Cliffe et al. 2011). This survey also revealed that forty-one per cent of respondents, who upon diagnosis reported they did not want children, changed their mind after becoming aware of the advances in the prevention of vertical transmission. Other authors have noted this previously (McDonald 2008). The section to follow discusses research with migrant HIV positive women, who are the largest group of newly diagnosed women in Ireland (O'Donnell, Moran, and Iggoe 2013).

### **2.3.3 The challenges faced by migrant mothers living with HIV**

During 2012, there were twenty-two new diagnoses among pregnant women in Ireland and fifty-five per cent of these women were born in Sub-Saharan Africa, ( O' Donnell, personal communication June 2013). Many of these women are asylum-seekers and are dealing with difficult social circumstances, including HIV.

There has been limited research with migrant HIV positive women, although two particular UK studies have provided insight into their lives (Ndirangu and Evans 2009, Doyal and Anderson 2005, Anderson and Doyal 2004). These studies reveal that they face a variety of challenges. Ndirangu and Evans (2009) examined the experiences of eight African HIV positive women in Nottingham, UK stating that they face:

A dual challenge in terms of coping with a life threatening chronic illness and adjusting to a new country (p.112).

They reported that being a migrant impacts on one's wellbeing, as many are asylum-seekers and the uncertainty concerning this can persist for many years (Ndirangu and Evans 2009). Asylum-seeking women have to deal with many restrictions until their immigration status is resolved and these can include not being able to work or travel home, and having to live in designated shared accommodation.

Anderson and Doyal's earlier study (2004) explored the experiences and challenges faced by HIV positive African women living with HIV in London. This mixed-method study with sixty-two participants found that these women had to deal with a range of social concerns, including poor housing conditions, the stigmatising nature of HIV, and the difficulty of coping without a nearby family or community network. Although these participants (many were mothers) had access to high standards of healthcare, their social conditions and networks were very different from those in their home countries and they reported having to negotiate many social hurdles whilst also caring for their families. Doyal and Anderson's (2005) second paper from this study examined the mothering experiences of participants in more detail using a narrative approach. Participants reported that parenting was difficult, as many were physically unwell, had sick children, were rearing their children without extended family support and in some cases had left older children in their home country (Doyal and Anderson 2005). Importantly, HIV was only one of multiple challenges that these women dealt with and their maternal identity was very important to them in that it gave them a reason to survive the disease and live a normal life (Doyal and Anderson 2005).

However, Doyal and Anderson's (2005) paper only gives a brief synopsis of the mothering experiences of the participants, despite the large sample. Nonetheless, the findings provide insight into the experiences of one of the largest groups of women living with HIV in the UK, as it is estimated that over forty per cent of heterosexual people in the UK with HIV are African women (Health Protection Agency 2012). The UK studies discussed have relevance for the Irish HIV situation because both countries have a high representation of African asylum seeking mothers in their HIV figures (Health Protection Agency 2012, O'Donnell, Moran, and Igoe 2013).

Foreman and Hawthorne's (2007) qualitative study (n=52) with HIV positive migrants (most were women of reproductive age) in Ireland reported that the Irish asylum seeking system is restrictive, as it discourages asylum seekers' integration into local communities and places many constraints on asylum-seekers, for instance they cannot work or claim benefits,

regardless of their health status. Many live in shared housing, often with a lack of proper cooking facilities. There is no doubt that their reasons for seeking asylum and subsequent migration can influence their physical and emotional health, as many are traumatised, so HIV is one of many issues they have to deal with. Additionally, Sheehan (2013) posits that Irish based asylum seekers often experience social isolation, so may remain on the margins of Irish society irrespective of their HIV status.

Another Irish based study with HIV positive African migrants (half of whom were mothers) also found that social challenges, including discrimination and self-enforced isolation, were a concern (Cairde 2003). While health outcomes have improved for those with HIV, the social impact remains, particularly for migrants. As already highlighted, African migrant women constitute the largest proportion of newly diagnosed women in the UK and Ireland (Ndirangu and Evans 2009, Foreman and Hawthorne 2007). Nevertheless, few studies have examined the lives of this group. Despite the well-documented psychosocial challenges of being an HIV positive asylum-seeking woman, positive adjustment does occur for some. Research by Dibb and Kamalash (2012) found that the key elements for positive adjustment after an HIV diagnosis for migrant women were an increased sense of spirituality and maintaining a positive attitude. A common theme through the research with HIV positive women is the social impact of HIV, specifically the issue of HIV stigma, which the next section considers.

#### **2.3.4 How stigma affects mothers living with HIV**

Stigma has long been associated with individuals with HIV (Bernays 2011). Simbayi and colleagues (2007) assert that HIV may be the most stigmatised condition in the world and argue that stigma affects HIV treatment and prevention. Indeed, HIV individuals are often held responsible for their infection, due to its association with sexual promiscuity and illicit drug use. A considerable amount of HIV related stigma literature exists (for example, Bernays 2011, The National Stamp out Stigma Campaign 2007, Sayles et al. 2007, Flowers et al. 2006 and Herek 2002).

Stigma is a process based on the social construction of identity (Goffman 1986) and a way of categorising and devaluing people. Goffman (1986) originally defined stigma as a socially discredited attribute, behaviour, or reputation that can potentially take over an individual's identity. Individuals may stigmatise themselves (felt stigma) or be stigmatised by others



(enacted stigma Goffman 1986). More recently Herek (2002), drawing on Goffman's seminal work, proposes that stigma is:

An enduring condition, status, or attribute that is negatively valued by a society and whose possession consequently discredits and disadvantages an individual (p. 595).

The process of felt stigma can contribute to an individual being more isolated and experiencing feelings of negative self-worth (Corrigan 2005). According to Link and Phelan (2001), there is a possibility that the individual will adopt a stigmatised stereotype and it will have negative psychological consequences for them. They further suggest that stigma occurs when:

Labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold (Link and Phelan 2001, p. 367).

In their research with African HIV affected communities, Campbell and colleagues (2007) define stigma in this context as "any negative thoughts, feelings or actions towards people affected by HIV or living with AIDS" (p.404). Furthermore, this definition of HIV stigma acknowledges that individuals living with HIV feel a sense of being devalued even if they have not experienced actual discrimination (Bernays 2011). Steward and colleagues (2008) support this view of HIV stigma, as they too acknowledge the existence of the devalued status of those who are HIV positive in some communities. This thesis adopts Campbell and colleagues' (2007) interpretation of HIV stigma which is the sense of being devalued because of one's HIV status and explores how it relates to HIV positive mothers. Fear of judgement can contribute to the isolation of affected individuals within communities and this interplay between social and psychological factors drives HIV related stigma (Campbell et al. 2007).

Herek (2002) contends that some of the reasons HIV individuals are stigmatised because it is often considered a condition that is avoidable and poses a risk to others, therefore those with HIV may attract judgement from others (ibid). These judgements from society seem to persist, despite the improved HIV health outcomes due to HAART. Steward and colleagues (2008), building on earlier health stigma work by Scambler (1986), describe three components of HIV stigma, dividing it into interpersonal behaviours towards those who are infected, and intrapersonal reactions to the situation an HIV positive individual finds himself or herself in. The first component, known as enacted stigma refers to acts of prejudice directed towards

those who are HIV positive (Steward et al. 2008). The intrapersonal experiences of HIV positive people can be described as felt stigma, that is, how they perceive they are treated by others, including family and friends, because of their diagnosis. Internalised stigma, the third type of stigma, manifests as a negative self-image due to the HIV status (Steward et al. 2008). These three types of HIV stigma can affect an individual's wellbeing and Hunter (2009) asserts that the way HIV positive women deal with stigma is bound up with their identity as mothers, as they weigh up the consequences of potential stigma on behalf of their children rather than as individuals.

Research has shown that acts of discrimination are often linked with HIV stigma (Lekas, Siegel, and Scrimshaw 2006). Campbell (2009) further argues that HIV related stigma could be addressed by developing HIV-competent communities. These communities are characterised by embracing a collaborative approach to tackling HIV prevention and care of those living with the disease. This adoption of competent HIV care and prevention approaches in affected communities can be facilitated by strengthening links with external organisations (Campbell 2009) and focuses on building communities to take ownership of HIV care and prevention and in turn address HIV stigma. It could be argued that, within an Irish context, non-statutory HIV support agencies are examples of HIV-competent communities, as part of their role is to reach out to wider society in an attempt to reduce HIV stigma. Recruitment of participants for this study took place in a Dublin-based HIV peer support centre, an example of an HIV-competent community.

A number of recent studies have revealed that stigma is still an issue for HIV positive women. Doyal and Anderson (2005) reported that their research subjects experienced HIV related discrimination and isolation within their own communities. McDonald's (2008) study with Australian mothers reported that many experienced stigma from unexpected sources such as family and friends. Hunter's (2009) feminist study with Canadian HIV positive mothers drew on stigma theory to explore the management of the social impact of HIV by mothers. Hunter reported that HIV positive mothers wanted to access support agencies but failed to do so because they were afraid of the consequences it might have for their children if it became known that their mother had HIV (Hunter 2009), and were therefore socially isolated. This perception of stigma by HIV positive mothers has emerged in other studies and may be due to a belief that HIV positive mothers might attract additional stigma because of societal assumptions about their childbearing/rearing capabilities (Hunter 2009, McDonald 2008, Sandelowski, Lambe, and Barroso 2004).

Kennedy (2012) maintains that HIV positive immigrant women attract stigma, relating to a lack of understanding of cultural practices around fertility and motherhood within these groups. Lekas, Siegel, and Schrimshaw (2006) propose that a perception exists that only certain types of women become HIV positive, for example, women who are sexually promiscuous. Therefore, stigma is linked to women's experience of living with the virus (Sandelowski, Lambe, and Barroso, 2004) and their mothering experiences (Nelms 2005). Mothers with other life-limiting or chronic illnesses do not usually experience stigma attributed to their condition, with the exception of mental illness. Lekas, Siegel, and Schrimshaw (2006) emphasise that felt stigma remains "The primary adaption challenge facing women with HIV/AIDS" (p. 1165) even in this era of HIV normalisation.

Lekas, Siegel, and Schrimshaw's (2006) longitudinal US-based study sought to explore the stigma experiences in two different groups of HIV positive women (some were mothers) prior to and since the advent of HAART. This study concluded that there was little difference in the stigma-related experiences of the two groups, in spite of the advances in HIV treatment (Lekas, Siegel, and Schrimshaw 2006). This concurs with Bernay's (2011) recent study that questions the assumption that HIV normalisation would reduce the stigma associated with the condition. Therefore, it appears that this assumption is too simplistic, as it appears that stigma remains an issue for HIV positive women.

In Ireland, researchers conducted a series of national surveys on HIV related stigma and discrimination (Stamp out Stigma, 2007). Seventy-three HIV positive respondents completed the questionnaire; forty-four per cent of respondents were female. Key findings from the HIV positive respondents include that the belief that those with HIV are viewed negatively is higher among HIV positive individuals than the public and they had experienced a high incidence of discrimination by health and social welfare staff (Stamp out Stigma, 2007). Other studies with HIV positive women support the contention that generic health care staff can be judgemental (Sanders 2009, Mc Donald 2008, Flowers et al. 2006, Nelms 2005). It is more than likely that this affects disclosure decisions when using general health services. However, disclosure is an on-going issue for those who are HIV positive and to follow is an exploration as to how HIV positive women manage telling others about their diagnosis.

### 2.3.5 Dealing with disclosure

One of the most significant challenges faced by those living with HIV is disclosure of their diagnosis (Bravo et al. 2010) and this persists in the HIV normalisation era. Deciding not to disclose one's HIV status may limit access to community and social support (Wouters, Meulemans and Van Rensburg 2009, Flowers et al. 2006). Disclosure of HIV status is important for coping, as it can give rise to increased social support (Walulu and Gill 2011, Wouters, Meulemans and Van Rensburg 2009, Flowers et al. 2006). Eustace and Ilagan's (2010) concept analysis paper defined HIV disclosure as a multifaceted process involving:

Making a voluntary or involuntary decision about whom to inform about one's serostatus, why, when, where and how (p. 2096).

Arnold and colleagues (2008) link HIV identity with the HIV disclosure process, arguing that the way in which an individual adjusts to their post-diagnosis identity appears to impact on their disclosure decisions. Sharing one's HIV status is a complicated undertaking, involving many different circumstances and relationships. HIV disclosure can include telling potential sexual partners, children, employers and health professionals. Each disclosure episode will have a different outcome and therefore it is understandable that those living with HIV would have concerns as to how to handle disclosure. The decision to disclose or not has consequences for the individual living with HIV. Wouters, Meulemans and Van Rensburg (2009) argue that the perceived negative consequences of HIV disclosure may outweigh potential positive outcomes. Importantly, research has shown that culture and ethnicity influence rates of HIV disclosure (Bravo et al. 2010, Eustace and Ilagan 2010, Flowers et al. 2006). Ndirangu and Evans (2009) propose that:

In many African settings, AIDS is framed within a judgmental and moralising discourse that condemns women for perceived sexual promiscuity (p. 11).

It is probable that this discourse leaves a legacy with HIV positive African migrants. Moreover, Eustace and Ilagan (2010) found that African HIV positive individuals from high prevalence areas living in the West are less likely to disclose than non-Africans; this reluctance to tell others may be related to their experiences of HIV/AIDS in their home country and their own beliefs about the type of individuals who become infected. Foreman and Hawthorne's Irish study (2007) also examined the social impact of HIV with Sub-Saharan African migrants living in

Ireland. A key issue that emerged from this research was that the possibility of discrimination from within their own communities affected whether they planned to disclose their HIV status, and often it caused them not to tell others (Ibid).

Ndirangu and Evans (2009) found that the HIV positive African women in their UK based qualitative study were also reluctant to tell others about their diagnosis. For participants in their study, many of whom had children, perceived stigma from within their own communities was the largest barrier to disclosure. In turn, this concern prevented them from accessing HIV-specific support agencies (Ndirangu and Evans 2009). Indeed, participants with insecure immigration status expressed a fear of both HIV-related discrimination and stigma which limited their support opportunities. However, there is no guarantee that increased social support will happen following disclosure (Wouters, Meulemans and Van Rensburg 2009), so reluctance is understandable in some circumstances. This perceived social exclusion serves as a barrier to coping with being HIV positive in those who disclose to very few; this fear of stigma, in turn, may lead to non-disclosure of their HIV status, and contribute to psychosocial difficulties. Therefore, HIV disclosure is a circular process and for mothers, disclosure to their children is an additional decision they struggle with (Hunter 2009).

Due to the advances in HIV antiretroviral treatments, most HIV positive women give birth to HIV negative babies. These women still have to decide, however, whether, when and how to share their diagnosis with their children. While many studies report maternal disclosure to children, few recent studies have looked systematically at this issue. One review by Murphy (2008) considered maternal disclosure from a US perspective in some depth. This investigation reviewed factors that influence disclosure and non-disclosure by mothers and the impact on their children. The complexity of the maternal disclosure process is affected by mothers' desire to protect their children; participants did not want to burden their children with the knowledge that their mother had a life threatening condition. Other studies have reported this (Hunter 2009, Wilson 2007). On the contrary, Murphy (2008) contends that children of HIV positive parents who know about their parents' HIV status largely adjust well to the news. Delaney, Serovich and Lim's (2008) review proposed that maternal disclosure decisions are based on the perceived maturity of the child to deal with it and non-disclosure has consequences for older children. Older children who have not been told may suspect something is wrong and experience distress at not knowing what the issue is within their family (Hunter 2009, Murphy 2008). Hawk's (2007) literature review on HIV maternal disclosure revealed that delaying disclosure is common, this postponement may be due to

mothers attempting to protect their children but also their significant others from the potential effects of stigma and discrimination (Hawk 2007). Some delay telling children because they do not know how it would affect them (Hunter and Longhurst 2013, Hunter 2009, Hawk 2007). Ironically, those women who could benefit most from social support often do not tell others about their HIV status. Consequently, they in turn experience barriers to accessing support from within their own social networks/communities (Davis, Frankis, and Flowers 2006). The women in Doyal and Anderson's (2004) study talked about the centrality of non-disclosure in their lives; many had not told their family in their country of origin since they considered disclosure a process that should be done face-to-face and, due to their immigration status, they had difficulties travelling home. The news of an HIV diagnosis would be received differently by family in Africa due to wide stigmatisation of those with HIV (Brandt 2008). As demonstrated, disclosure of one's HIV status is complicated for mothers and does affect support options. The next section draws on research with HIV positive mothers, which considers their coping strategies and support needs.

### **2.3.6 Coping strategies and support needs of HIV positive mothers**

Pittiglio and Hough's (2009) US-based study considered the coping strategies of African American mothers with HIV. This study comprised a secondary analysis of mixed data collected in the early 2000s (as part of a longitudinal study) and it drew on coping strategy literature to inform its findings. Mothers reported using positive coping strategies including acknowledging and dealing with their disease and the benefits of seeking support as a coping mechanism (Pittiglio and Hough 2009). However, the findings, while useful, cannot be generalised to all mothers living with HIV as the group was urban-based and was comprised predominately of low-income African-American women. Additionally, data collection occurred within a few years of the introduction of HAART. The impact of HAART on HIV disease progression was not evident at that time and so it might have been more worthwhile to re-interview these women instead of revisiting the original data; interviewing them as their children reached adulthood, when they could reflect retrospectively on their lives, would have been particularly insightful. Other studies have explored the role of support networks for those living with HIV, as support can be in many formats, for example, support groups, online forums and respite care.

The inter-relationship between social support and psychological well-being was evident in a UK based phenomenological study with thirty HIV positive Africans (Flowers et al. 2006). Many

of the research participants were women (17) and this study found that fear of stigma contributed to many participants deciding not to disclose their HIV status to friends or family. Flowers and colleagues further report that those who had told no-one apart from their medical team had few support options; not telling others could have a negative effect on their emotional wellbeing as they lacked opportunities to meet peers living with HIV (Flowers et al. 2006). According to Walsh and colleagues (2012) social support buffers the psychosocial effects of life with HIV but it may be difficult to access due to the perceived stigma and fear of discrimination. HIV organisations and medical settings can provide a structure for known HIV positive individuals to meet each other.

Social capital as a way of theorising social cohesion within communities can be of assistance to individuals. Putnam (1995) originally proposed Social Capital Theory, which emphasises the value of social, networks/ties and supports utilised by individuals that can be mutually beneficial. Social connectedness is essential to social network development. Individuals maintain networks because they are an important resource for them (Ferlander 2007). Putnam (1995) describes two main types of social capital as bonding and bridging. Bonding social capital refers to the existence and value of close ties, trusting and supportive relationships within a local community (for example, the HIV positive community). Veinot (2010) argues that bonding social capital emphasises the importance of emotional support between socially similar individuals and can help an individual cope better with an illness. Within the context of HIV, community-based organisations that have evolved to support those who are living with the disease can facilitate network development between socially isolated affected individuals (Ibid); it also encompasses the context within which people can work collectively to achieve goals of mutual interest (Ferlander 2007). This would be evident in HIV support agencies. Bridging social capital is concerned with how individuals from differing social contexts can work together for mutually beneficial motives and involves cross cutting ties across different community groups. An example of this within the context of this study would be an HIV charity and a mental health user group working together to address stigma.

Drawing on the work of Pierre Bourdieu (1986), Ferlander (2007) suggests that two levels of social capital, individual and collective exist. The individual level is concerned with the returns an individual receives by accessing networks to support his or her health. Bourdieu proposes that social capital is linked to an individual's material and cultural wealth and relates to their place on the social hierarchy (Osbourne, Baum and Ziersch 2008). Drawing on the work of Putnam (1995), Ferlander (2007) describes collective social capital as generalised social trust

across social networks. Within a health context, social capital identifies the various forms of social networks accessed by individuals or communities who are dealing with a health challenge. Green and Tone (2010) argue that social support can be protective against ill health, and supporting this Blaxter (2010) advances that higher social capital levels within communities are associated with reducing mortality rates.

Linking this benefit of effective social capital could have some applicability to those with HIV, because many individuals with HIV are isolated and may have limited safe social networks (Veinot 2010, Flowers et al. 2006). As noted earlier, stigma and fear of discrimination remains a feature for HIV positive individuals and it limits support opportunities. Campbell and colleagues' (2005) South African based study provides a useful example of how social capital can facilitate and improve HIV prevention with young people. This research highlighted the difficulties involved in creating effective social environments to facilitate sexual health promotion with young people in HIV-affected communities, concluding that because young people were marginalised, the effectiveness of HIV prevention targeted at them was compromised (Campbell et al. 2005). The potential of social capital theory to support HIV prevention is evident, as social capital theory considers both the individual and group aspects of social networks.

Indeed, when relating Putnam's notion of social capital to health, it encompasses both the social and biosocial aspects of health, but as Blaxter (2010) points out, it fails to take into account how politically different societies distribute power and resources. She further contends that social capital may be over-reliant on community organisations whose influence will vary according to the political climate of a country (Ibid). HIV communities are diverse and their needs will differ between a European country and an African one, and so one size of social capital will not necessarily fit all HIV communities. In Ireland, the HIV community has representation from across the world, including migrants from Africa. Despite the shortcomings of Putnam's social capital theory, social support helps mothers living with illnesses to cope better (Power et al. 2011). It may be a useful lens through which the support needs of HIV positive mothers in the HIV normalisation era can be understood. It can facilitate the identification of both bonding and bridging social capital as it applies to these mothers in Ireland.

Mothers living with HIV have to balance parenting with the other impacts of the diagnosis. As already noted, the perceived difficulties mothers may have in telling others about their HIV



status may limit their opportunities for support compared to mothers living with other illnesses. The significance of social support for mothers living with HIV emerged from Walulu's (2011) recent research, as many of her study participants reported that networking with peers proved useful as it helped with practical issues around dealing with the illness. The need for women to seek support outside of family networks relates to the difficulties around disclosure to loved one's (Walsh et al. 2012). These mothers need to manage their own healthcare needs while caring for their families. Their support needs are important due to the exceptional demands brought on by this diagnosis (Walsh et al. 2012). Adedimeji (2010) suggests that HIV positive individuals need to use network and community-based resources to generate support, signifying the value of bonding social capital in addressing their needs. In time, effective support could reduce the risks and maximise the positive consequences of HIV disclosure (Wouters, Meulemans and Van Rensburg 2009) which is an on-going issue, as the next section demonstrates.

### **2.3.7 The significance of existing research for this study**

The studies reviewed have explored various aspects of the maternal HIV experience. The literature considered how illness affects mothers (Vallido et al. 2010) and argues that when mothers are dealing with an illness, care giving/parenting may take priority over mothers' own healthcare needs. Critically, this review has illustrated the importance that having children has for women who are HIV positive (Cibulka 2007, Barnes and Murphy 2008, Sandelowski and Barroso 2003a). Studies reveal how an HIV diagnosis affects mothers (Walulu's 2011, Hawk 2007) and the uniqueness of receiving an HIV diagnosis when pregnant (Kelly et al. 2012, Kelly, Alderdice and Lohan 2009, Long 2009, 2006).

The multidimensional impact of maternal HIV infection is also apparent, as stigma remains a concern (Hunter 2009, Flowers et al. 2006, Lekas, Siegel and Schrimshaw 2006, Doyal and Anderson 2005). There is no doubt that disclosure is difficult for mothers living with HIV (Hunter 2009, Delaney, Serovich and Lim 2008, Hawk 2007) and culture and ethnicity influence HIV disclosure decisions (Bravo et al. 2010, Eustace and Ilagan 2010, Ndirangu and Evans 2009). For HIV positive migrant mothers, HIV is one of the many challenges they face as they deal with uncertain immigration status and difficulties associated with living in a foreign country (Ndirangu and Evans 2009, Flowers et al. 2006, Doyal and Anderson 2005, Anderson and Doyal 2004). The significance of social support for women living with HIV emerged,

particularly when newly diagnosed (Walsh et al. 2012, Walulu and Gill, 2011), although the perceived difficulties they may have in telling others about their HIV status limits their opportunities for support (Hunter 2009).

Much of the research to date with HIV positive mothers has been situated within the dominant biomedical discourse focusing more on outcome than on experience. Qualitative research with HIV positive women who have children, while valuable, has lacked a mothering focus from the onset. Importantly, motherhood or mothering intentions were the focus of concern in a minority of studies examined (Walulu's 2011, Cibulka 2007, 2006, Hunter 2009, McDonald 2008) but most of the data was collected in the early years of HAART. The studies scrutinised have mainly adopted qualitative approaches to explore various aspects of the mothering experiences of HIV positive women. A couple of studies adopted narrative methodology (McDonald 2008, Doyal and Anderson 2005). Some understanding of the issues that face these mothers have been evident, though a lack of contemporary focus taking into account the advances and developments in HIV management is apparent. Research from high prevalence HIV areas where HAART is not accessible to all who need it shows HIV is one of many challenges. In Ireland, HAART is universally available and the take-up rate and adherence is high. Consequently, research must now focus on how HIV positive mothers face life in the HIV normalisation era. This thesis will explore the lives of Irish based HIV positive mothers in a treatment-normalised HIV country.

## 2.4 Summary and conclusion

The evidence from the studies reviewed suggests that this Irish based study is timely and significant for several reasons. It will be a current exploration of the experiences of a group of HIV positive women with children. The improvements in HIV treatment and MTCT interventions have influenced the HIV maternal experience. Yet it seems that, regardless of the centrality of being a mother for HIV positive women, their lives are still complicated by psychosocial factors. HAART has had a positive impact on physical health, but HIV is a difficult condition to live with, therefore gaining an understanding of affected mothers' experiences in the HAART era will offer insight into their lives.

This research will adopt a narrative methodology to elaborate on current understandings and give insight into the mothering experiences of a group of HIV positive women living in Ireland. In research reviewed earlier in this Chapter, it is evident that there is a lack of theory in understanding their experiences, proposing there is scope for applying a consistent theoretical framework to explore the experiences of mothers living with HIV. This research will draw on a combination of theoretical perspectives concerning HIV normalisation (dominance of biomedical care), feminist mothering, and 'mothering on the margins', HIV stigma typologies, specifically the writings of Campbell and Herek, and HIV disclosure as it applies to these mothers. Finally, social capital theory will support an examination of the support networks of these mothers in Ireland. This in-depth study will use multiple theoretical perspectives to address the research question; that is, gain understanding of the lives of Irish- based MLH in this HIV normalised era. The next Chapter presents the research methodology selected and the study design. It also addresses the data collection process and analysis.

## ***Chapter Three: Methodology***

### **3.1 Introduction**

The previous Chapter examined the literature pertaining to mothers living with HIV and it was evident that there is a paucity of research on mothering while HIV positive, particularly from an Irish perspective. Accordingly, as little is known about the lives of mothers living with HIV, there is a need for further research in this area in order to explore and gain an understanding of their mothering experiences. This study seeks to contribute to that process through adopting a narrative approach.

This Chapter presents the study's methodological framework. Elucidating the narrative accounts of mothers living with HIV requires a research design that allows for the documentation and interpretation of the mothers' stories. The Chapter opens with a discussion about the selection of a narrative research methodology and why it was deemed the most suitable approach for this study. The next section presents a description of the research process, including ethical approval procedures, gaining access to participants, sampling, and data collection. This is followed by a discussion about the data management and analysis techniques and the role of reflexivity as it applies to this study.

### ***3.2 Section one: Narrative research***

Narrative research encompasses a broad range of approaches; it collects, interprets, and analyses storied texts or personal accounts (Riessman 2008). In narrative analysis, the story is the 'object' of investigation as it describes an event, action, or experience from the perspective of the narrator. Mishler (1991, 1986) originally proposed three main categories of narrative research. The first category examines the structure of event narratives and is exemplified in the work of Labov and Waletzky (cited in Patterson 2008). These researchers developed a text-centred model to evaluate personal event narratives. Event narratives are structured into a six-part model using a series of questions to describe the event (Patterson 2008). The second category is the experience-centred narrative approach which attempts to identify and interpret the link between narratives and experiences. It is influenced by phenomenology and considers that through analysis of the collected stories, experiences form part of an

individual's consciousness (Squire 2008b). The third narrative category is concerned with the social context of narratives (Squire 2008a) and how collected stories represent broader cultural representations (Riessman 2008). In relation to the current study, adopting a narrative experience-centred approach enables the women to tell stories about their lives as HIV positive mothers and establish how they relate to the broader HIV agenda.

According to Elliott (2005), narratives are a way to represent and understand events that are significant to the narrator. In support of this, Moen (2006) reiterated the meaning-making of narratives through the story-telling process. The interactive process of story-telling (Ricoeur 1984, cited in Crossley 2000) allows events to be drawn together so that they make sense of one another. Holloway and Freshwater (2007) identify that the use of narrative research methods in health research is increasingly apparent and can be useful to help the narrator make sense and give meaning to a health-related experience. Stephens and Breheny (2013) and Stephens (2011) promote the use of a narrative approach in research examining disruptive health experiences, for instance dealing with an HIV positive test result. Narrative researchers argue that the story is led and controlled by the narrator and can be transformative, in that it can generate change in thinking about an experience and show how individuals adapt (or not) to their new circumstances. Additionally, Holloway and Freshwater (2007) suggest the process of telling one's story can confirm or enhance one's identity following a disruptive health experience.

### **3.2.1 Rationale for conducting a narrative study**

Deciding on study methodology involves matching the research aim and questions with the most suitable research design. This research was exploratory so it was most suited to a qualitative approach which emphasises the way the world is constructed (Sandelowski 2008) using non-numerical data to gain understanding. The philosophical underpinning of this study is interpretivism as the study aims to gain an understanding of the lives of HIV positive mothers. By adopting an interpretive approach, it is possible to conduct an in-depth inquiry into their lives (Hale, Treharne and Kitas 2007). Creswell (2006) proposes that qualitative research adopts an emerging approach to the inquiry and its use is evident in research reviewed in Chapter Two with HIV positive women (Bernays 2011, Brandt 2008, and Sandelowski and Barosso 2003a) across a variety of contexts. Selecting the most suitable qualitative method involved an examination of key elements of certain methodologies, in

order to decide the most appropriate methodology for this inquiry. A study's philosophical and theoretical underpinnings influence its methodological approach and the research question. A grounded theory approach generates theory from the data collected (Cutcliffe 2000), as it examines processes in order to identify patterns in the development of social interactions (Starks and Brown Trinidad, 2007). This approach has been used in a variety of HIV studies (Walulu 2011, 2007, Barnes and Murphy 2009, Ingram and Hutchinson, 2000, 1999) as seen in the literature review Chapter. This approach would have been appropriate if this study was attempting to generate a theoretical account of how HIV positive women cope with mothering. However, my research is concerned with exploring and gaining an understanding of their lives as mothers and considering how the participants make sense of their lives through the stories they tell (Murray 2008).

Phenomenology is also a popular choice for research with HIV positive individuals (Sanders, 2009, 2008, Flowers et al. 2006, and Nelms 2005) and has made a significant contribution to HIV psychosocial research. Caelli (2001) argues that phenomenology emphasises the commonality and essence of a particular experience but is not concerned if change in thinking about the experience occurs. It tends to focus on homogenous groups who share a common phenomenon. This study's sample is heterogeneous, comprising of women at different points on the motherhood trajectory, from both high and low HIV prevalence countries, and consequently demands a different research approach.

Narrative research can be useful when seeking the patient's perspective in order to inform clinicians and policy makers (Gregory 2010, Thomas et al. 2009, Overcash 2003). Examples in Chapter Two include Anderson and Doyal's (2004) research with HIV positive African women in London which used a narrative approach to gain insight into their experiences (see also Doyal and Anderson 2005). Similarly, in her Australian study, McDonald (2008) adopted an open narrative approach to examine HIV positive women's mothering intentions and experiences. More recently, to support her study findings, Brandt's (2008) case study narrative research with HIV positive women in South Africa drew on Frank's chaos narratives (1995), Crossley's loss of the future with HIV positive individuals' work (2000) and Bury's biographical disruption theory (Bury 2001, 1991, 1982). However, while these narrative studies with HIV positive women include reference to mothering experiences, none solely focuses on mothering and so their contribution to understanding the phenomena of mothering while HIV positive is inadequate.

The use of a narrative approach allows for exploration and interpretation of the women's narratives to reveal their lives and identifies how the narratives relate to the broader HIV agenda, for example the manner in which disclosure is managed while taking into account the potential for discrimination and stigma. This research study is exploratory and the story telling process is central to the study design. The choice of a narrative approach facilitates participants to describe and make sense of their experiences through the stories told during the interviews. Stephens (2011) asserts the story of the narrator is rarely prioritised in biomedical research and she argues that the value of adopting a narrative approach in collecting illness stories is that the voice and story of the narrator is heard.

The overarching epistemology of this study relates to mothering in the context of HIV disease and it aims to interpret meanings of these experiences within the collected narratives (Gregory 2010). Compared to either grounded theory or phenomenology, narrative research values the story telling process as well as the story content. Supporting this study's epistemology involves drawing on a feminist approach, as the focus is on the mothers' experiences, specifically their perspectives on their lives as HIV positive mothers (Harding 1991). Sarantakos (2005) claims that the emphasis of feminist research is to document women's experiences as they are experts in their own lives (Brayton undated), therefore can complement narrative methodology. Furthermore, feminist research places importance on women's position in society and seeks to explore this (Sarantakos 2005). This study seeks to investigate the lives of mothers living with HIV who, it could be argued, are not that visible in their own right within the wider HIV arena, apart from interventions to prevent vertical transmission, and so adopting a feminist narrative stance to support the study gives priority to their subjective experiences.

### **3.2.2 Challenges of narrative research**

A number of authors have highlighted the complexity of narrative research design. Riessman (2008) draws attention to the fact that stories are often told out of sequence and that in real life research interviewees drift off the point while telling their stories. Indeed the temporal sequencing of a narrative and how the narrator feels about the event may be hard to distinguish during analysis (Patterson 2008). Narrative analysis can be time-consuming and few specific narrative analysis methods exist (Elliott 2005). Gaining an understanding of how an individual makes sense of a particular experience is difficult (Elliott 2005). Certainly, Mishler

(1986) proposed that one of the central challenges in narrative research is accounting for how the expressions of lived experiences are related. The analysis of narratives from interviews differs from other qualitative research approaches, in that the narrator controls the story and collaborates with the researcher to produce an account of the experience in question (Holloway and Freshwater 2007), in this instance being an HIV positive mother. The narrator and researcher co-construct the narratives (Riessman and Quinney 2005) and they are shaped through this dialogue (Gregory 2010). Understanding the co-construction of narratives is central to much narrative enquiry; this valuing of the interview context influences the analysis and interpretation of collected narrative accounts (Mishler 1991, 1986).

### **3.2.3 Experience-centred narrative research**

This study adopts an experience based narrative approach to gain insight into the meaning of the experiences for mothers living with HIV. Squire (2008a) describes the underlying principle of experience-based narrative research as the:

Phenomenological assumption that experience can through stories, become part of consciousness (p. 41).

An experienced-based approach is concerned with gaining a full understanding of the narrators' experience and emphasises the transformative function of narratives. According to this approach, narratives are chronological, significant and allow sense to be made of a particular experience, for example how one comes to terms with one's HIV diagnosis. Narratives are reconstructed over time and may reflect a change in an individual (Squire 2008a, 2008b). This approach to collecting narrative allows for the incorporation of the wider political, social, and cultural contexts that may influence and/or shape an individual's story about an experience. Experience-centred narratives can be wide-ranging, including stories about a 'turning point' in an individual's life, for example a disability following an accident or becoming pregnant when HIV positive and can also include written and visual materials as such diaries or videos. Semi-structured interviews with an open conversational style are most commonly used (Squire 2008b) involving a relatively small number of participants who share a common experience such as mothers with HIV.

In this study, the use of Murray's framework for analysis of narratives (Murray 2009, 2000) supports the experience-centred approach to allow for a broader interpretation of the stories.



This method, which is based on earlier work by Doise (1986 cited in Murray 2000) adopts an experience-centred approach and focuses on four specific elements of narratives. These elements are the personal, interpersonal, positional, and ideological (Murray 2000, 2000, Shelton and Johnson 2006).

The Personal focuses on how an individual presents their experience. The Interpersonal examines the interaction between the participant and the interviewer and how the narrative evolves during the interview. The Ideological establishes how stories relate to cultural/societal contexts and identifies social representations within the narratives. Finally, the positional level of analysis focuses on the differences in social position between the narrator and the researcher (Murray 2000). The table below summarises each level as it applies to this study.

Personal	Possible examples from this study would include pregnancy experiences, stigma management and how being HIV positive has affected identity/life expectations.
Interpersonal	This level considers the interview context and how it shapes the narrative. It also considers the co-construction aspects within the narrative.
Positional	The analysis level extends aspects of the interpersonal level and examines the differences in social position between the narrator and the interviewer in the interview context and how that influences the process.
Ideological	This level is concerned with exploring the broader social and cultural elements within the narratives, for example, the stigmatisation of those who are HIV positive and how participants feel their own experiences relate to cultural expectations of mothering.

**Table 1: Murray's analysis levels**

As the table establishes, Murray's model allows for the understanding of experiences from different perspectives. Warnes and Daiches (2011) drew on a variety of narrative methodologies including Murray's narrative analysis approach in their study of maternal

experiences of young women. Using this narrative framework allowed the researchers to develop insight into how the dominant societal ideologies about motherhood influence and add to the complexity of their mothering experience. Murray's (2009) research with women with breast cancer used this analytical approach to present an in-depth understanding of their illness experiences. Their stories illustrated how they made sense of their illness and its impact on their lives (Murray 2009). Similarly, Shelton and Johnson (2006) adopted Murray's approach in their study of delayed motherhood. Murray's framework allowed the researchers to gain insight into how participants perceived themselves in relation to contemporary representations of mothers in Western society. The findings confirmed the paradoxical nature of delayed motherhood as it reported that participants struggled with their own maternal experiences and tried to relate these to dominant maternal ideologies (Shelton and Johnson 2006). The studies just discussed demonstrate the usefulness of the narrative approach in gaining insight into maternal experiences. This approach is a useful tool in meeting this study's aim of exploring the mothering experiences of HIV positive women. Whilst the discussion in this section has focused on the use of Murray's framework, the next section considers the limitations associated with this approach.

### **3.2.4 Limitations of an experience-centred narrative approach**

Complex research designs can feature when adopting a narrative methodology and few frameworks exist to guide the analysis of experience-centred narratives. As the individual's experience is the primary concern, there can be a tendency not to consider narrative structure and language during analysis. This in turn can lead to over- or misinterpretation of the narratives (Squire 2008a) which may result in over-strong assumptions being made about what a participant said during an interview. However, Murray's framework involves a number of levels to move beyond personal narratives to see how they relate to broader social processes (Murray 2008, 2000). Accordingly, this structure reduces the possibility of misinterpretation. The consideration of broader social processes relates well to HIV, which impacts on many aspects of the lives of affected mothers. Additionally, this analytic approach does consider language features, including metaphors and the tone of the narrative, as both support the interpretation of meaning within a personal story. Whilst the discussion so far has focused on justifying the choice of narrative methodology for this study, the next section considers the research framework for this study.

### **3.3 Section two: Research process**

The aim of this study was to explore the experiences of a group of mothers living with HIV in Ireland using an experienced-centred narrative approach. A description of this study process is now presented.

#### **3.3.1 Research setting and gaining access**

Participants were recruited through an HIV support<sup>2</sup> centre in Dublin city, Ireland. This peer support setting emphasises empowerment for those who are living with HIV and has approximately 800 members registered. Members include Irish, European and African gay and heterosexual men and women. Many attend daily or weekly to use a variety of services available at the centre. Of the current members, 37% are women; the majority (70%) from ethnic minority groups. Most of the members of the centre also attend one of the two HIV treatment centres in Dublin. Recruitment through this voluntary sector setting was preferable, as interviewing in a more natural context in the community rather than a hospital setting was an advantage. The venue complemented the narrative approach of this study, as participants were familiar with the environment, which facilitated the interviews to be as relaxed as possible.

To access participants, I met with the centre manager and explained the study and type of sample I wanted to recruit and he agreed to facilitate the recruitment of mothers from the centre following consultation with the centre's management team. The centre manager is the organisational gatekeeper who, in this instance, assumes responsibility for the facilitation of the research agenda and activities within the organisation (Lee 2005). A short document outlining the research project (Appendix 5) was submitted for review by the management team.

Following review of this document there were a few recommendations and some proposed changes to the original Participant Information Sheet (Appendix 1) and the proposed recruitment plan. They suggested that a support worker recruit mothers directly instead of using poster invitations, as I had originally planned. The women's support worker was briefed about the study and the inclusion and exclusion criteria. She handled contact in the first

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<sup>2</sup> For the purpose of confidentiality, the research setting will be referred from this point on as *the HIV centre*.

instance and provided me with the contact details of five mothers per month over a three-month period. The support worker also gave potential participants the Participant Information Sheet (Appendix 1) to read in advance. Any mothers who agreed to participate were contacted by phone by me to arrange an interview time at the *HIV centre*.

### **3.3.2 Ethical Considerations**

The study received ethical approval from the Health Research Ethics Approval Panel at the University of Bath in November 2010. Researching with HIV positive individuals is challenging from an ethical standpoint. For this study, issues that warranted ethical consideration included gate keeping, the consent process and protecting the identity of the participants. Particular attention was paid to the personal and sensitive nature of the information sought in the interviews. I based my study upon the ethical principles of respect for every individual, autonomy, non-maleficence, beneficence and justice.

Elliott (2005) notes that research involving human subjects must consider the potential impact of participation. Riessman (2008) emphasises that narrative co-construction is challenging from an ethical perspective, as the stories evolve during a conversation between the narrator and the listener. During analysis and interpretation the researcher needs to be cognisant of the uniqueness of the endeavour. One of the challenges of narrative based interviewing from an ethical perspective is the centrality of the relationship between the researcher and the narrator. Establishing trust early is important as it facilitates the narrator to feel at ease Josselen (2007) emphasises that this relationship between narrator and listener is essential in narrative interviews particularly when the research is sensitive, as in this study. This trust requirement demands that the researcher adopts the highest ethical principles to ensure protection of participants' interests throughout the lifetime of the study; from seeking formal written consent, to the manner in which the interviews are conducted, and the safe management of the interview transcripts. Therefore, key considerations for this study were the sensitive nature of the study, confidentiality and informed consent.

### **3.3.3 Sensitive Research**

There is some debate as to what constitutes a sensitive topic in research. A sensitive topic can be judged as such due to a participant's personal circumstances and or the relationship between the narrator and the interviewer (Hyden 2008). Mothering, as a topic, is not sensitive

but a personal journey within a larger social and cultural context. Due to their HIV status, the personal circumstances of the participants deem this particular study sensitive. McDonald (2008) asserts “research with HIV positive women is intrinsically personal and sensitive (p. 36)” as HIV remains a highly stigmatised condition which affects an individual’s relationships, work, and future (Squire 2010). Many HIV positive individuals do not share their diagnosis with family and friends so may be wary about speaking about their lives. It was always clear that the participant could discontinue an interview at any time. The mechanisms for support after interviews were included on the Participant Information Sheet (Appendix 1). In addition, the research ethics committee advised me to include details of how child protection issues would be addressed if a concern emerged during the interview. The initial Participant Information Sheet was amended to incorporate how disclosure regarding child safety would be dealt with if an issue arose. Confidentiality and informed consent were additional factors that were addressed prior to the study commencing.

### **3.3.4 Confidentiality**

Participant anonymity was of particular concern to the ethics committee. I was vigilant about protecting their identities throughout the study and only documented participants’ first name. Pseudonyms were allocated to each research participant and their children, and hospital names were changed. The confidential nature of the study was reiterated by the researcher to the mothers prior to the interviews. All personal information given as part of the study was kept confidential to safeguard the women’s privacy. Conducting research in Ireland with a small sample from a small population made the principles of confidentiality more demanding. Names and demographic information of all participants were stored separately. The transcripts were password protected on my computer.

### **3.3.5 Informed Consent**

It was made explicit that participation in this study was voluntary and that participants could withdraw at any stage. As mentioned earlier, the support worker at the *HIV centre* gave the Participant Information Sheet to all potential mothers (Appendix 1) to read, before they decided if they wished to participate. They were advised to return the sheet to the staff at the *HIV centre* or to destroy it after they had read it. Prior to the interview commencing, I provided another opportunity for them to read the Participant Information Sheet and discuss any

questions they had. All participants completed the consent form (Appendix 2) prior to the interview and these were stored separately from interview transcripts.

### 3.3.6 Sampling

Purposive sampling, a common feature of qualitative research, is a deliberately non-random method of sampling a group of people with a particular characteristic (Bryman and Teevan 2004) i.e. mothers living with HIV. A maximum variation sample was recruited (Patton 2002) as the study set out to gain insight into a variety of perspectives (Creswell 2006) of mothering with HIV. This study aimed to interview participants with multiple understandings of mothering who were at different points on the motherhood trajectory and came from both high and low HIV prevalence countries. Accordingly, African-born, European and Irish mothers with both older and young children participated. As a group they could be considered 'hard to access' due to their HIV status.

Sampling in narrative research can involve small samples, as it focuses on collecting in-depth stories (Holloway and Freshwater, 2007). Baker and Edwards (2005) argue that when deciding on a sample size in qualitative research, one of the central influencing factors is how many interviews are necessary to produce the desired outcome, that is, meet the study's aim and objectives. In this instance, the study was exploratory and a heterogeneous group of mothers were sought to attempt to gain understanding about their lives.

This type of sample was information rich and allowed for the identification of emergent common patterns (Patton 2002) of the shared experience of mothering with HIV. It was planned that fifteen mothers would be interviewed. This number was deemed sufficient in consultation with my research supervisors, as the in-depth analysis of the collected narratives would yield rich data; it was felt that this was more important than how many interviews were conducted (Baker and Edwards 2005).

Inclusion criteria were established beforehand and were as follows:

<b>English speaking HIV positive mothers aged over 18 who were members of the <i>HIV</i> centre.</b>
--

<b>Mothers who have had an HIV diagnosis for at least 6 months to ensure that they had had time to have baseline medical checks done.</b>
<b>Mothers with children over six months as their HIV status would be established by then.</b>

**Table 2: Inclusion criteria**

These inclusion criteria ensured that participants were not newly diagnosed, were aware of their children’s HIV status and spoke English. The exclusion criteria for the study included pregnant women and HIV positive mothers who were not confident speaking English.

### **3.3.7 Data collection**

The development of an interview guide (Appendix 3) allowed for questions that related to themes from the literature review and research objectives to be included. This guide supports the conversation in a flexible manner, as the aim of these interviews was to collect first-hand experiences (Gregory 2010) from the mothers. Having an interview guide allowed for divergence from specific questions to capture individual experiences during the conversation. The topics included their experiences of being a HIV positive mother (including positive aspects), whether they had experienced discrimination or stigma due to their HIV status and what support networks they accessed (Appendix 3).

Prior to commencing the study, a mother who was HIV positive agreed to take part in the pilot interview. This interview allowed for checking of the practicalities of the interviewing process, for example, refinement of the interview questions, checking digital recording equipment, and dealing with any unforeseen problems in advance of data collection commencing. Following the pilot interview, I was more comfortable with the digital recording device and my interview questions and style. As already discussed, there was a rationale behind each inclusion and exclusion criterion and one participant had been diagnosed within the last six months. In this instance, the interview continued as the woman was keen to participate. Fifteen mothers volunteered to participate and when contacted by phone some declined to be interviewed or could not make it despite being offered many appointments. Some of those who failed to attend for the interview (which were mainly in the morning) said they had difficulty setting the time aside as they had to be available for school pick-ups, hospital appointments or work which took priority. There was no financial incentive offered to potential participants to participate and eleven mothers were eventually interviewed.

### 3.3.8 Interviews

All the interviews were audio recorded using a digital recorder and the interviews took place in the *HIV centre* between January and June 2011. The length of the interviews ranged from twenty-three minutes to one hundred minutes, with an average time of fifty minutes. Written consent was sought prior to the interview. I checked that all participants understood what the interview was about. Some required assistance with this task as they did not fully understand the purpose of the research study prior to meeting me. In addition, a brief demographic information form was developed and completed at the end of each interview (Appendix 4). Each interview commenced with an opening question asking the women to talk about their experiences as an HIV positive mother. Many responded to this question by describing their diagnostic experience or telling how many children they had. Some had difficulty starting and asked me for guidance. In this instance, I asked them to tell me about their children or when they were diagnosed, as these appeared to be the natural starting point for other participants.

Additionally, I asked participants about their lives as HIV positive mothers, disclosure to others and, if they had experienced discrimination or stigma, what support networks they used. I adopted a conversational and free flowing style during the interview to allow the women's accounts to be collected, while acknowledging the sensitivity of the topic. Gregory (2010) stresses that interaction between the narrator and researcher is of utmost importance during the interviews, my attention was therefore always directed towards the narrator. A couple of challenges arose during the interviews. For example, one interview took place in the dining room area of the *HIV centre* as there had been a mix up with room bookings. We were disturbed a few times with background noise but the participant was happy to continue despite these interruptions. Another mother brought her young daughter with her to the interview as she had no-one to mind her. During this interview her daughter required attention and as a result, there was significant background noise on the recording that affected the transcript of that particular interview. After each interview, I wrote down my own observations and reflections on each interview before I left the *HIV centre*. The interviews were transcribed verbatim by a transcriber as I received a small seed grant from my employers to support my study. I worked closely with the transcriber during the preparation of the transcripts and checked the completed transcripts with the audio files to ensure they were accurate.



Each transcript was reviewed many times to ensure familiarity with the data, to correct spelling inaccuracies and to change participants and their children's names and remove hospital names to protect anonymity. Bird (2005 cited in Braun and Clarke 2006) contends that the process of transcript review can be an integral part of the interpretation stage of analysis, as it facilitates understanding of the data (Braun and Clarke 2006). Specific challenges that arose when using a transcriber who was not familiar with HIV/medical terminology were the use of HIV-specific references, for example, 'viral load' or 'antiretrovirals' and medical terms which were misspelt by the transcriber. The audio recordings of the interviews were difficult to follow in parts, for instance, if participants spoke in a low voice or if English was their second language, so it was easier for me to listen to and identify gaps in the transcripts to ensure they were as accurate as possible (Braun and Clarke 2006). The process was time-consuming but worthwhile to ensure I was familiar with the interview data as Poland (2002, cited in Gubrium 2002) argues, producing interview transcripts can be challenging from a quality perspective due to the subjective nature of the task and the potential for error which can affect the validity.

### **3.3.9 Data management and analysis**

The interview transcripts and audio recordings were transferred to the software package NVivo 8. NVivo 8 is a specialist tool developed solely as a computer aided qualitative data analysis system (CAQDAS). This tool facilitates coding and analysis of text, video and audio data (Wainwright and Russell 2010). NVivo 8 manages and supports qualitative analytical work and has two benefits over manual data management. It allows the researcher to consider a variety of sources while coding, that is both text and audio information. Secondly, NVivo 8 maintains a clear audit trail that facilitates transparency (Wainwright and Russell 2010). The process and stages of coding are tracked, so that researchers can demonstrate clearly their rigorous approach to data analysis. The use of NVivo 8 facilitated the management and exploration of the data in an efficient manner, as it allowed me to explore and retrieve different avenues of enquiry in the transcripts. Preliminary coding of significant stories within each interview allowed for the generation of a list of free codes across the transcripts while staying with the data and to search for meanings within them. These included diagnosis stories, stories about telling family members about their HIV status and the importance of peer support. In total 160 free codes were identified (Appendix 6). These codes were then grouped into hierarchical

codes to identify key narrative statements or excerpts within the transcripts. Sixty-seven hierarchical codes emerged (Appendix 6).

Using NVivo 8 facilitated the mapping of significant narratives while keeping the research objectives in mind. Open coding, i.e. generating free-standing codes, allowed me to look at all the elements of the collected narratives to underpin and support my narrative analysis. Then I sorted them into a range of narrative threads, for example, receiving HIV diagnosis, telling others about their diagnosis, to preserve the narrative and access the rich data from the transcripts. During this phase, the meaning that these experiences held for the mothers was considered by examining how they spoke about actual events/experiences, for example, describing meeting other women at the *HIV centre*. This involves identifying narrative tone and metaphors as both help to evaluate how an individual understands an experience.

My intention in writing up the analysis was to produce sufficient evidence of the narrative material around each story theme to support my interpretative assertions. The analysis focused on identifying the personal narratives and the collective experience of mothering while HIV positive. As an iterative process, the focus on the analysis was to present a synthesis of the common and different experiences within the narratives. Another analysis consideration was the structure of the stories. How each woman recounted her story and answered questions demonstrated what was important to her. In each interview, multiple narratives occurred and the mothers returned to significant life experiences they had told earlier due to my comments or questions during the conversation. The overall collection of mothers' narratives allows access to shared meanings of mothering while HIV positive. As described earlier, data analysis was guided by both Murray's framework (Murray 2008, 2000) and key considerations of experience-centred narrative research. By adopting an experience-based approach, the focus is to gain an understanding of the narrators' experience, how in turn they make sense of it and emphasises the transformative function of narratives. Murray's four levels of narrative analysis (see table 1) involves scrutinizing transcripts to examine the narratives to understand what it was like to mother while HIV positive and to illuminate how participants made sense of their lives through the stories they told.

### ***Personal analysis***

In the excerpts presented in the Chapter four, many participants' stories were future- focused and progressive (Gergen and Gergen 1983) as their circumstances improved over time, notwithstanding the challenges HIV brought to their lives. In the progressive narratives, the

narrators were generally optimistic about their lives. Contrarily, other narratives were more regressive, in which the content was about felt stigma, non-disclosure, and the challenges of being HIV positive. Additionally in some accounts, participants were positive about aspects of their lives, for example their future career plans, but had reservations about telling others.

Murray (2009) suggests that within narrative accounts characters feature, and examining and identifying the central character of a story through engaging in the analysis process is important. The analysis revealed that the mothers were central characters in their stories, although in some narratives their children featured a lot; the other dominant character in their stories was HIV. An interesting feature that was common across many of the narratives was that few women referred to HIV by name, using 'It', which is suggestive of a difficulty on some level around their acceptance of their diagnosis. Men were largely absent from the narratives although some spoke briefly about their ex-partners. Eight of the women were lone parents or widows. It is possible that relationships were difficult for participants to maintain, although this was not explored in-depth during the interviews. Whilst HIV plays a role to varying degrees in their identity, being a mother is a frame of reference for their daily lives.

### ***Interpersonal analysis***

The emphasis of this study was on co-construction of the stories (Murray 2009, 2000). Prior to data collection, I anticipated that because I am also a mother it would influence the conversation; contrarily, only a couple of the women asked me if I had children and this was after the interview had finished. Another factor that may have shaped the interviews was that with the Irish mothers, the conversation flowed more easily because of a common language and shared cultural understandings compared to the interviews with the migrant mothers, some of whom spoke English as a second language. Additionally, most participants stressed how normal their lives were as typified by Sabine a mother of one who said:

I want to be normal, I want to live life like a normal person, and it's the same like any other mother, you know?

Within their narratives, many of the women emphasised the joyful elements of their lives, associated largely with how important their children were to them.

### ***Positional analysis***

The positional level of narrative analysis extends the intrapersonal level to consider the differences between the researcher and the narrator and how this influences the co-construction of the narratives. As a middle class white researcher/nurse lecturer, there were obvious differences between the research participants and myself, while as mother I could relate to some of their mothering experiences. McMahon, Murray and Simpson (2012) propose that the positional level in health research needs consideration, particularly when an interaction is between a patient and a health professional. They contend, that as the balance of power may lie with the health professional, this may inhibit the individual in telling their story, particularly if the interview takes place in a hospital or clinic setting (ibid).

Certainly, the interview setting i.e. the *HIV centre* helped to address positional differences between the mothers and myself. The mothers accessed the *HIV centre* regularly; this may have helped them to feel comfortable telling me their stories. While my professional background as a nurse may have influenced my interviews, I was not actively involved in the care of the participants and their identity as patients was not particularly strong during the conversations.

### ***Ideological analysis***

At this level of analysis, how participants perceived themselves in relation to contemporary representations of mothers in Western society and HIV was considered. Riessman (2008) argues that:

A good narrative analysis prompts the reader to think beyond the surface of a text, and there is a move towards a broader commentary p. 13.

This study's accounts, presented in more detail in Chapter Four, illustrate the complex relationship between societies' constructions of mothering and the reality of mothering while HIV positive. This study presents a shared meaning of HIV positive mothering, while taking into account the challenges of living with the condition in the HIV normalisation era. It also illustrates how being a mother influences other aspects of being HIV positive, for example, preventing vertical transmission, and maternal disclosure to children. As the primary care givers for their children, they deal with everyday parenting and their stories relate to the broader dominant HIV narrative of 'normalisation'. Indeed, they did appear to perceive themselves as patients as their main concern was their child, which leaves them little time to

think about themselves. As mothers, they focused on the future as many were well and getting on with their lives. The excerpts in the following Chapter demonstrate how they chose to minimise the impact of HIV in everyday life by seeing themselves as regular mothers, by not allowing their HIV positive status to interfere with work, study or future career plans.

Within their narratives there was some incongruence, as despite the assertions that HIV was a minimal part of their lives, certain mothers contradicted this. For example, describing scenes of hyper-vigilance when any blood spills occurred at home, dilemmas about disclosure to family, and on-going concerns about perceived stigma were described. This reflects how individual mothers, while well and healthy, still had to deal with the psychosocial aspects of being HIV positive.

Management of information around disclosure meant that HIV governed some of the participants' lives, as some experienced judgement from family and had to live with the consequences of that. Those who told very few people about their HIV status spoke of living with the threat of HIV stigma and discrimination. Research reviewed earlier supports the on-going HIV-related psychosocial concerns, although most studies are not specific to mothers (Bravo et al. 2010, Flowers 2010, Ndirangu and Evans 2008). Hunter (2009) contends that the difference for HIV positive mothers is that most of their psychosocial concerns are dealt with by them as mothers first rather than as individuals, for example they were more concerned about the consequences of disclosure on their children than for themselves.

The use of Murray's (2008, 2000) analysis levels gave structure to the narrative analysis process for this study. It facilitated me to integrate the different levels to gain understanding of the maternal HIV experience from different perspectives and the embedded meaning of those experiences over time. Using a multi-level approach enabled a detailed exploration of the meaning within their stories of HIV positive mothering while thinking beyond the personal aspects of the narratives by considering social and cultural contexts of the narratives. A summary of the analysis levels is in Table 3.

Personal	Participants identified their diagnostic and pregnancy experiences. How they dealt with stigma and their concerns about telling others with particular reference to sharing the news of their diagnosis with their children. How they found attending the HIV centre and meeting peers.
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Interpersonal	<p>Two distinct contexts:</p> <ol style="list-style-type: none"> <li>1. The interviewer-interviewee interaction during the interview.</li> <li>2. How the interview setting i.e. the HIV centre shapes the narrative.</li> </ol> <p>It also considers how the narratives were co-constructed focusing on my interjections, comments, advice given. This level also examines how the stories were conveyed and what was emphasized e.g. for some the unexpectedness of the diagnosis was described in-depth while others focused on disclosure decisions.</p>
Positional	<p>This level focuses on how the differences between myself as a nurse researcher and how or if this influenced the storytelling during the interview. e.g. at times during interviews some women sought advice from me in relation to health matters.</p>
Ideological	<p>This analysis level revealed how narrative content showed how participants perceived themselves in relation to the following:</p> <ul style="list-style-type: none"> <li>• Contemporary representations of mothers in Western society.</li> <li>• Constructions of HIV.</li> <li>• Stereotyping of those who are HIV positive.</li> <li>• HIV stigma.</li> </ul>

**Table 3: Key threads within each narrative level.**

### 3.3.10 Reflexivity

The place of the researcher is central to experience-centred narrative research (Riessman 2008). As Holloway and Freshwater (2007) emphasise, narrative researchers need to be open about, and to, the analytic process, reporting not only the narrative and plot, but also their own response to its progression.

Being self-aware is paramount to most research, however during a narrative research study, self-awareness has a higher significance as I too was a participant in the research process, co-

constructing the narratives with the women and, in turn, interpreting meanings within their stories. My analysis reflects my own story on three levels; because I have previous experience as a nurse caring for HIV positive individuals, because some participants referred to my professional knowledge during the conversations, and because I am a mother too.

During one interview the participant began crying very early in the interview and had difficulty answering the questions; it became apparent that she was depressed and expressing suicidal ideation. As I had worked previously as a mental health nurse I have the necessary skills to deal with this situation, but in this instance I was a researcher, so I ended the interview and sought help from one of the support workers to deal with the distressed woman. In addition, as a mother, listening back to the interviews was, at times, emotionally difficult as the women recounted experiences which were very different to my own life. However, this brought home to me the value of this type of research, in particular the need to document their stories of mothering, as HIV research to date has given little consideration to the personal experiences of mothering while HIV positive.

Being reflexive during a narrative study ensures the maintenance of trustworthiness throughout the process (Holloway and Freshwater 2007). Willig (2001) argues that there are two types of reflexivity; epistemological and personal, and these are interrelated. Epistemological reflexivity focuses on examination of the origin of the research question and assumptions that arise during the research process. As just discussed, my motivation to study mothers living with HIV arose from my previous nursing experiences and I was also aware that this influenced my leaning towards a qualitative, specifically a narrative, methodological approach to generate an account of their experiences. Personal reflexivity considers how individuals' own values, experiences and interests influence their research project (Willig 2001) and so overlaps with epistemological reflexivity. I had worked with mothers when HIV treatment options during pregnancy were limited during the late 1990s and had seen the devastation of losing a child to AIDS as part of my clinical work. When I decided to undertake a doctoral study, I wanted to explore the current experience of mothering with HIV as my clinical nursing experiences with HIV positive mothers had left a lasting impression on me and so I was not value free in my research decisions.

To aid the process of reflexivity I kept field notes recording my impressions of the interviews. I also had to be aware of how my interviewing style varied through each interview. For example, at times during some interviews, I gave advice to some participants which demonstrated my

difficulty in maintaining a neutral role during some interviews. In addition, the memo writing process during data analysis was also an opportunity to review and maintain self-awareness (McGhee, Marland and Atkinson 2007). The reflexive process was on-going throughout my project and the challenge was to maintain an awareness of how my social identity and professional experiences influenced the research process (Robson 2002 cited in McGhee, Marland and Atkinson 2007) to ensure that the study remained valid and authentic. Although participants were offered the option of reviewing their interview transcripts, none actually requested to read them so member checking did not happen in this instance.

### **3.3.11 Trustworthiness**

Riessman (2008) argues that trustworthiness is critical in establishing the validity and reliability of a narrative study and proposes that correspondence, persuasiveness and coherence are criteria that warrant consideration. This section explains these three criteria in relation to my research project.

- Correspondence relates to historical truth to ensure that findings are consistent with knowledge. This study did not set out to produce a factual report of participants' mothering while HIV positive but a credible one, as the study aimed to gain an understanding of the lives of MLH. Accordingly, verifying the facts of their stories was secondary in this instance. I also offered participants the option of reviewing their interview transcripts, although none of them accepted this offer.
- Riessman's (2008) second criteria, persuasiveness, relates to how convincing I was in my interpretation of the stories. I linked excerpts with theoretical data while referring to the context of the interviews aided by Murray's analysis framework. Persuasiveness also relates to the extent to which the study findings are useful for other researchers and are supported by a clear audit trail. Using NVivo to manage this study's interview data allowed for a comprehensive record of the data analysis process (Appendix 6) to support the study findings and claims.
- Riessman (2008) states that adopting a reliable narrative analysis approach is essential in addressing coherence, the third criterion of trustworthiness. Most of the mothers told their stories in a cohesive fashion, although a few were less coherent and presented fragmented stories which were difficult to follow at times.



Murray (2008) argues that narratives and their subsequent analysis are concerned with organising the disorganised and giving meaning to them. Recently, Hyvarinen and colleagues (et al. 2010) questioned the dominance of establishing narrative coherence when interpreting narratives and suggested considering the value of incoherent or broken narratives in establishing how meaning is constructed through narratives (McLeod 2011).

### **3.4 Summary and conclusion**

This Chapter presented and explained the methodology adopted for this study. The study set out to explore the lives of HIV positive mothers in Ireland through a narrative qualitative study. I have described the rationale for adopting a narrative approach. This Chapter also presented the actual research process including recruitment, sampling decisions and ethical considerations. Data collection through in-depth interviews and the analytic methods were explicated. In total, eleven narrative interviews were completed and the collected narratives were personal, diverse and insightful. The next Chapter presents the study findings.

## **Chapter Four: Findings**

### **4.1 Introduction**

The Chapter is presented in two sections, section one opens with thematically grouped personal narratives concerning diagnosis and pregnancy experiences. The narratives in section two describe the psychosocial impact of HIV as it pertains to the study participants. It includes narratives about disclosure, how mothers continue to protect their children from HIV, and support networks. Two types of narrative text are presented, some excerpts are individual descriptions of experiences and others include conversational exchanges between the participants and myself. Pseudonyms are used to refer to each research participant and their children. As part of Murray's analysis process (Murray 2008, 2000), a summary of each interview was prepared and is included in Appendix 6.

#### **4.1.1 Profile of participants**

Eleven mothers were interviewed between November 2010 and June 2011 and they had twenty-one children between them. Table 4 contains brief demographic information about each woman.

<b>Name</b>	<b>Age range</b>	<b>Years diagnosed</b>	<b>Marital status</b>	<b>Family situation</b>	<b>Country of Origin/ Citizenship</b>
Kate	41-50	22	Married	Two sons (primary school age)	Ireland
Maud	20-30	1	Single	One daughter (toddler)	Cameroon/ asylum-seeker
Evelyn	51-60	7	Widow	Two adult sons(six grandchildren)	Zimbabwe/ leave to remain

Joanne	31-40	17	Single	One teenage son	Ireland
Barbara	51-60	3	Separated	Three adult children	Ireland
Grace	20-30	9	Widow	Three sons (two in Africa, eight year old with her in Ireland)	Cameroon/ asylum-seeker
Sabine	20-30	2	Single	One daughter (toddler)	Eastern Europe
Sharon	41-50	11	In relationship	Two daughters (one adult, one primary school age)	Ireland
Elisabeth	22-34	7	In relationship	Two daughters (primary school age)	South Africa/asylum-seeker
Rose	31-40	12	Separated	Two sons and one daughter.	South Africa/asylum-seeker
Ciara	20-30	3	In relationship	One daughter (primary school age)	Ireland

**Table 4: Demographic information**

#### ***4.2 Section one: becoming a HIV positive mother***

Many of the women used their diagnosis as the starting point for their story. They learnt of their diagnosis at different times during their childbearing years; for some it was before they had children, others were already mothers and the remainder were diagnosed because of antenatal HIV screening. Four women underwent testing after becoming aware that a previous or current partner was infected, one found out after a blood donation, another was ill in hospital when tested, and two had an HIV test after receiving a diagnosis of a sexually transmitted disease. The remaining three women were pregnant when diagnosed. Their diagnosis experiences are presented here using excerpts from selected interviews that encompass common reactions to the news of an HIV diagnosis.

### 4.2.1 Diagnosis before having children

Two women received their diagnosis before they became mothers and a description of their diagnosis experiences follows. Their narratives reveal the shock of the diagnosis itself. Kate, an Irish mother of two and ex-nurse, has been living with HIV since 1988 and spoke about her diagnosis early in the interview:

Kate: They were doing it at the hospital, “come on down and donate blood,” off I skipped along with a number of other people and when I was called in to the blood transfusion centre to hear what was wrong. They recommended, you know, they called me in at the transfusion centre and the lady who spoke to me said, “well, do you have any idea why you are here?” Well obviously there is something wrong with my bloods but I said that the only thing I could think of was I had an uncle who had died of leukaemia. I was thinking of cancers of the blood, and no, no, so she had to, I think it was difficult for the person telling me because she knew I had no clue, and I didn't. Anyway, the doctor did give me that result and gave me the name of a hospital that had a clinic that I could go to. I went there on whatever day it was on and I nearly died of shock going in because just the whole atmosphere was tense and frightening and the other people sitting in the room, they were all male at the time, they were all white males, and clearly some of them had obvious symptoms of being very unhealthy. I just thought what has happened here, what am I doing here? I didn't believe it. I was in utter shock. I went home from that and said I would never go to a hospital again.

The dominant tone of this excerpt is disbelief at her situation, for example, Kate describes the other patients (all male) waiting in the HIV clinic as unhealthy and so very different to her (healthy). Kate did not see herself as someone with HIV; she did not identify with other HIV positive patients in the first instance. Within this excerpt, she reveals how a normal event became very significant for her, and her initial feelings and thoughts about what happened to her. It is worth noting at this point that this event happened over twenty years ago but Kate's vivid description reflects the continuing emotional impact of the diagnosis.

In 2009, another participant found out she had HIV after a herpes diagnosis. Sabine, who was originally from Eastern Europe, described what happened:

Sabine: I went for a test because I got herpes. I got herpes and I went to the hospital, at the same time they told me I am HIV. It was a shock, you know, I was in shock, I could never think, you know, I could get it.

Like Kate, the HIV positive result was unexpected for Sabine as she did not perceive herself to be at risk for contracting it. Their responses upon hearing the news were similar, as both felt unprepared for the possibility that they could be HIV positive. This lack of preparation for their HIV diagnosis appears to be due to a perception that they were in a low risk category; accordingly, HIV was not relevant to them prior to diagnosis.

#### **4.2.2 Mothers diagnosed HIV positive**

Seven of the women already had children when diagnosed. Sharon, an Irish mother of two, was diagnosed HIV positive while ill in hospital. The disbelief of being told she was HIV positive featured early in Sharon's interview:

Sharon: 1999 that's when I found out, ah that was a disaster, me partner, I was with him for years, he was an ex drug user and he had it (HIV). We used condoms, we were safe. I ended up getting a cold, chest infection and I couldn't breathe and just went down to about six stone, didn't know what was wrong with me, hadn't got a clue. Then I went up to the hospital, some doctor transferred me to another hospital, they told me there that I was HIV. I nearly died, I couldn't believe it because I didn't know what was wrong with me. When I was first diagnosed everything went through me head, the eldest girl, because I sort of raised her alone since she was two, and here I was, if anything happens who's going to look after her?

A notable feature of Sharon's extract is the presence of 'orientation framing' as Labov (1972) would describe it, as the story starts with explicit mention of the year of her diagnosis. The unexpectedness of the diagnosis is evident in her use of the expression "I nearly died" when she heard the news, even though she was in a relationship with a known HIV positive man. Her astonishment at her diagnosis suggests that she had little knowledge about HIV. Sharon appeared not to have considered that she might be HIV positive, although, on hearing the news she immediately had concerns about her child's future should anything happen to her (Sharon).

More recently, Maud was diagnosed in 2010 after she came to Ireland from Africa. Her HIV test was part of a routine health screening for asylum-seekers. Upon diagnosis, similar to Sharon, her thoughts quickly turned to her young daughter:

Maud: I just asked the doctor am I going to die and leave my child, you know, he really reassured me, reassured me, so I was sent to the hospital and they were really nice so they gave me some information about the whole thing,

then they referred me to the HIV centre. I had nobody to talk to actually, right, so I just booked myself in and just cried, cried, cried. Yes I was very worried, obviously I thought I was going to die, you know, I was just thinking about her and what would happen to her and I was worried as well as she got it, but they sent me to the children's hospital and carried out some tests on her and she was negative.

Maud's description reveals the difficulty she had in dealing with the news. As a recently arrived migrant mother, her previous knowledge of HIV in Africa may have influenced her reaction to her diagnosis, as her initial concern was how long she would live. On diagnosis, Maud appeared to know very little about HIV and its treatment, assuming she would die soon and leave her young child. Testing her child became a priority to establish if she had infected her daughter while pregnant, signifying that the possibility of vertical transmission dominated her reaction to her own diagnosis. Maud's relief at the confirmation of her daughter's negative status was reassuring for her.

An HIV diagnosis appears to have been a traumatic event for these mothers, as they were concerned that their children could be infected too, which was emotionally difficult for them. Some participants spoke about having their children tested for HIV. Sharon's teenage daughter was, however, unaware that the tests she was undergoing were for HIV:

Sharon: I had the other young one, she was only thirteen. I had to bring her for tests and she wasn't impressed and she kept asking me what are they doing, and I just said, I think I just told her they were blood tests. She was giving out to me but I said you'll be alright because it (HIV) can lie low in your body for years, and you don't know. I kept saying to myself if she has it, that's all I need just before I have the baby, but they said no she was grand so that was a bit of relief.

Sharon hid the real reason for the tests from her daughter even though her current partner was not her daughter's father. This process happened while she was still adjusting to her own HIV diagnosis, when her knowledge about HIV was poor, as she was unsure about the possibility of her daughter having HIV.

On diagnosis, Ciara, an Irish ex-intravenous drug user, had a four-year old daughter. Vertical transmission was not a worry she had to deal with, as she explained:

Ciara: I had Aoife before I was infected with it, HIV, so it doesn't really affect her, she doesn't know anything about it like. I was a drug addict for twelve years, and I started going out with a fella and then when I found out he had it,

I got tested and the first one came back clear and then I had to go back three months later and that was positive.

Denise: So was it a big shock for you to find out?

Ciara: Oh yes, definitely, me whole world shattered because I didn't know much about HIV like, so I still don't know an awful lot, like. I kind of just, well I don't know, like whenever I found I had it, I kind of made a decision to get clean and I think it scared me, you know, so when I found out I had it like I made a decision to get clean and it turned me life.

In Ciara's account, the decision to have an HIV test was due to her partner at the time disclosing his HIV status. Despite her drug history, she admitted to not knowing a lot about HIV. Her use of the phrase 'me whole world shattered' is self-explanatory regarding the devastating impact it had on her. In spite of her initial reaction, Ciara's diagnosis brought positive benefits as she decided to undergo detoxification from opiates.

It was evident in the narratives that, upon diagnosis, these women were more concerned about the possible ramifications of the diagnosis for their children. These narrative excerpts illustrate that the primary concern of newly diagnosed mothers is establishing their children's HIV status and this concern impacts on their response and adjustment to their own HIV diagnosis. Overall, the news of the diagnosis was unexpected, despite the fact that some of the mothers were in relationships with known HIV positive men or came from a country of high HIV prevalence, suggesting there may have been a reluctance to confront their own susceptibility to the risk of infection. Some women in the study found out they were HIV positive when pregnant and an exploration of their experiences now follows.

#### **4.2.3 Being diagnosed when pregnant**

Three participants were diagnosed while pregnant, for two of whom it was due to antenatal HIV testing. A mother-to-be has to adjust to the diagnosis and deal with the possibility that her unborn child might also be HIV positive (Kelly et al. 2012, Kelly, Alderdice and Lohan 2009). As noted in Chapter Two, the emphasis of care for newly diagnosed pregnant women focuses on the prevention of vertical transmission, rather than on the women themselves; indeed preventing vertical transmission was also the central theme of this study's pregnancy stories.

In 2005 Elisabeth, a migrant woman from South Africa, pregnant for the first time, was not long in Ireland when she was diagnosed. She described what happened:

Elisabeth: When I was pregnant then I found out I was HIV positive. I was eight months pregnant. Yes, it was a shock and I was on my own, no family, and my ex-husband just neglected me, so it was a nightmare, a nightmare.

Denise: So it was late in the pregnancy?

Elisabeth: Yes, it was late, and my fear was what if the baby had HIV because I didn't have more knowledge even though I am from Africa, I've seen people die like in front of me. I was told as well that my child would be HIV positive so I had to go on meds. I had my daughter then, thank God she was HIV negative.

Elisabeth's reaction to her HIV positive result was influenced by her belief that HIV is a fatal illness based on her experiences in South Africa. As a first-time mother Elisabeth had to deal with the asylum process and adapt to a new country while adjusting to her diagnosis.

Another South African mother, Rose, was also diagnosed when pregnant although she had been diagnosed previously. She explained that:

Rose: In the back of my mind there was something vaguely bleak, like yes I am HIV positive but at that time, you know, they were not talking about it like now. I didn't believe it really in 1999, I knew but I didn't want to admit it, you know, ok I was not in denial.

Denise: Did you believe it?

Rose: No, I didn't believe it at all so I come to Ireland, I was diagnosed again in Ireland. My daughter, she is eight and was born in 2003, before that the process in the hospital, the check-ups when you are pregnant and all that, so I was also tested and then again, Jesus, this is reality, this is reality, the positive thing again, it comes again. I was confused, I was diagnosed in 2002, 1999, but the reality is 1999, but that time I was not sure, you know, you let it go over your head, life continues, then my daughter was born in 2003.

'Orientation framing' (Labov 1972) is evident, as Rose describes her HIV diagnosis experience by referring to significant dates. Her narrative tells of her denial at the first HIV diagnosis in 1999, as she had suppressed knowledge of her original diagnosis. The tone of this excerpt is stable as she goes through the events in sequence, but appears slightly removed from what



happened, which may reflect her denial of the initial HIV result. My interjection demonstrates that I needed clarity about her original diagnosis. She says that she did acknowledge that she was HIV positive when first diagnosed, but appears to have chosen not to deal with it. Certainly, it appears Rose remained ambivalent about her diagnosis when she received her HIV test result in 2002. While pregnant for the second time in Ireland, Rose appeared to be surprised by the result but did acknowledge her earlier diagnosis to herself. In her interview, Rose did not reveal whether she told her medical team that she had previously been diagnosed four years earlier. Her description of her diagnosis in 2002 was brief and she focused on talking about her children, despite it being the second time she had received the news.

Joanne, an Irish mother of one, became pregnant when she was twenty years old. At the time, she was in a relationship with a known HIV positive man and recounted that:

Joanne: I found out I was pregnant, I knew I obviously had HIV because it was just obvious I would have it if me partner had it. And then I was pregnant, so I just knew I had it from the time I got pregnant. Nobody even told me I had it, I just knew for some reason I had it. Then when I got the test there was a new drug out at the time called AZT and that was only on trials and they asked me would I like to be one of the first people in Ireland to try it, it's to stop the baby getting the disease, so I took that. Now in saying that, I didn't take it every day like I was supposed to take it because when you're first pregnant you're throwing up and I had morning sickness, and everything for months, so I didn't take it the way I was supposed to. I took it say every two days or something like that, and then because I wasn't with me partner I did feel like I was on me own. I was always worried about the baby catching the disease, that's what my most concerns were about, and then when I had him then I had to get a drip into me arm throughout the labour for, I think that was AZT, as well just to make sure the baby still didn't get it.

Joanne suggests that becoming HIV positive was inevitable and she appeared to be resigned that at some point she would be infected because of her relationship with a known HIV positive man. The narrative tone is of acceptance that she was destined to become HIV positive. As a first time mother-to-be, avoiding VT became her priority and the only treatment available at the time, the late 1990s, was Zidovadine (AZT, an antiretroviral). She was given AZT but admitted that, due to morning sickness, she did not always take it as prescribed.

Joanne recounted how she had to deal with her pregnancy on her own after splitting up with the baby's father. Her primary anxiety was for her unborn child, which appeared to reduce her concern for herself as a newly diagnosed woman. Receiving an antenatal HIV diagnosis can

bring unanticipated difficulties. For women in this situation, the possibility that their unborn baby could become infected means that strategies to prevent vertical transmission take priority. Within the general population, the assumption that HIV positive women will have HIV positive babies is common, as VT prevention strategies are not generally known (McDonald 2008), so these reactions are not surprising. It was apparent that for these women, the possibility of vertical transmission remained through the pregnancy while they received HAART and persisted until their child's HIV status was established.

#### **4.2.4 Being an HIV positive pregnant woman**

The women diagnosed when pregnant and those who became pregnant after diagnosis spoke about their pregnancy experiences. Five participants became pregnant post-diagnosis and three of them talked about this. HIV positive women's pregnancies differ from those of non-HIV positive women. As outlined earlier in Chapter Two, when pregnant, HIV positive women have to take medication (HAART) from the second trimester onwards to prevent VT, and their new-borns are subjected to numerous blood tests to establish their HIV status. This is unlike a 'normal' pregnancy experience, when most women will not even take paracetamol. Firstly, the pregnancy experiences of newly diagnosed women are presented.

As a first time mother-to-be, Joanne's pregnancy coincided with her diagnosis in 1999 when HAART was relatively new as an intervention to prevent VT. In her interview, she spoke about the anxiety she felt in the early months of her son's life:

Joanne: Ah yes I was worried until he was eighteen months old 'til I got the all clear, and I was always worried that he'd have it. I don't know what tests they do on them when they're babies, there was loads of test he had to get done, but they always said from the beginning they thought there was chance of him having it.

Joanne said earlier that she was one of the first pregnant women in Ireland to have AZT when its efficacy to prevent VT was still being established, so it is understandable that she expressed doubts about this new treatment. Her relief that her son did not become infected is apparent in the above excerpt, even though she recalled that the medical team had reassured her that the possibility of infecting him was slight. It is worth noting that in the late 1990s the use of antiretrovirals to prevent VT was established in high-income countries, including Ireland. Joanne and her clinicians would have had a different perspective on the efficiency of the

intervention compared to the African-origin mothers like Rose and Elisabeth who had experienced the devastation of HIV/AIDS in their home countries. As mentioned earlier, Rose was diagnosed for the second time late in her second pregnancy in 2002. Within the first five minutes of the interview, she recounted:

Rose: When you are pregnant to save the child you get treatment

Denise: And that worked, your daughter is ok?

Rose: She's negative ok, right. I learnt it made a difference for me, if I were in South Africa now I shouldn't be even living, my friends are gone, and everybody's gone, you know?

Denise: In South Africa?

Rose: Everyone's gone, people are gone, all died.

Rose's attitude to HAART was influenced by her experiences of HIV in South Africa where HAART was available to prevent VT before it became a treatment option for adults. The relief she felt in being able to get effective treatment in her second pregnancy is clear from this excerpt; she considered herself fortunate to have access to HAART. Becoming a mother is now a realistic option for many HIV positive women and in this study some women became pregnant after diagnosis and talked about this. Kate, a retired Irish nurse, lived with HIV for over ten years before she contemplated having a baby. She told me:

Kate: I began to see it (having children) as a possibility but still something that I was morally grappling with hugely, and not alone about HIV but the fact that my own mother died at the age of forty-eight of cancer, and had spent the previous maybe eight, nine years quite, quite ill, when I was just a teenager, and the impact of that on myself and my younger brother particularly. I feared that even if now there was a window where I might be able to have a child, my own experience of my mother's health and illness and the impact it had on us, I again wondered could I do this, could I have a child and what if I was then very, very, ill and the child grew up with a very ill mother?

Denise: And have to leave the child?

Kate: Yes, and have to leave the child. Anyway, all of that was constantly going around my head then I began to hear the biological clock and think I do want

to do this. A lot of women were having infected babies at that time but there was also beginning to be a bit more information available through the medical world on having a pregnancy, a safe pregnancy, and having a caesarean. My desire to be a mother became very big and it became very big with the knowledge that it could be done, so we had two children via 'turkey basting'<sup>3</sup> technique. My first pregnancy was fantastic, I was as healthy as I could have been.

Denise: Did you enjoy your pregnancy?

Kate: Loved it, absolutely loved it, it was fantastic. Sean was born by caesarean, it was wonderful I have to say, I didn't really care about it, I spoke to women who said 'well I want the whole experience' but why should I? I just wanted a baby, a healthy baby, I really didn't care if it landed from Mars but had our DNA.

As a first-time mother Kate's decision to become pregnant was a difficult one, but her desire to have a child occurred during the early 2000s when medications to prevent VT were more widely available. Another factor that affected her was the loss of her mother when she was a child and the impact that this had on her brother and herself. She acknowledged that her biological clock was ticking and she needed to decide whether to have a child or not before she got too old. Her husband was HIV negative so Kate used artificial insemination to conceive so he would not be at risk of contracting HIV. She was unconcerned that she had a caesarean section as long as the baby was hers and her husband's. Having a caesarean section can be seen as a disappointment for many non-HIV affected women, demonstrating how different the pregnancy experience was for Kate. Her account is stable and progressive although she had to contend with self-insemination to get pregnant and with taking antiretrovirals during her pregnancy. What is apparent from her account is her joy at being able to have her children after many years of living with HIV.

Another participant became pregnant shortly after her HIV diagnosis in 2009. Sabine, an Eastern European single mother, was in a relationship with an HIV positive man when she found out she was going to have a baby:

Sabine: It was a very, very easy pregnancy, it was no problem and I was working through all my pregnancy. I also trust doctors, you know, what they are saying, so I was happy she, she is all right, you know, she doesn't have it.

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<sup>3</sup> This term is commonly used to describe artificial insemination at home using a syringe.

Sabine's description of her pregnancy may reflect the contemporary HIV experience compared to Kate who had lived with HIV for many years. For Sabine, her pregnancy went well and she appeared to have a lot of confidence in the effectiveness of the drugs used to prevent VT. It is worth noting that both women were pregnant in the post-HAART era and so had access to antiretrovirals.

In contrast, despite being on HAART when pregnant, Sharon found the postnatal period difficult. She said:

Sharon: When I was pregnant with the little one it was very difficult. When I was having her I was given so much medication, then she had to get so much medication when she was a few weeks old and that was horrible. That's breaking my heart giving her that, you know, she was only a baby. I was worried, I knew why I had to give it to her but it broke me, it broke my heart giving it to her because she was only a baby. And she had to get certain vaccinations when she was born, whereas my other daughter didn't have to go through all that. And I thought it was just saying that maybe I shouldn't have had another child, she fought too much, it wasn't fair, then I felt guilty she had to get so much medication when she was a few weeks old and that was horrible.

Denise: Did you find that difficult?

Sharon: That's breaking my heart giving her that, you know, she was only a baby, you carry them around for so long, you don't want anything to happen to them.

The wording and tone of Sharon's excerpt vividly describe her struggle with taking medication while pregnant. The process of giving antiretrovirals to protect her new-born child was emotionally tough for Sharon. In this excerpt, she presents a picture of how overwhelmed she was with her situation, describing how she felt about giving her baby antiretrovirals. Sharon's struggle with administering antiretrovirals shows how her mothering experience differed from non-affected women. She also expressed feeling guilty that her baby had to have blood tests and take medication because of her HIV positive status. Sharon, like most of the mothers, just wanted to do her best for her child but it had an impact on her own wellbeing, as her narrative shows how psychologically distressing it was for her. Sharon revealed that she felt her first pregnancy was very different as it occurred before her HIV diagnosis many years earlier. It is possible that her reaction to her situation was heightened compared to that of Joanne, Kate and Sabine who were first time mothers-to-be.

Being pregnant while HIV positive can be an emotional and worrying time. Participants largely embraced VT interventions and all had access to medication to reduce the possibility of infecting their babies. In this study, all the mothers who spoke about being pregnant had HIV negative children; however, their pregnancies were emotionally challenging due to their concerns about the possibility of VT. These experiences are consistent with Kelly and colleagues' (et al. 2012) findings reviewed in Chapter Two that documented the disruptiveness of an HIV diagnosis during pregnancy. Importantly, in these excerpts the African-origin mothers appear to be affected by the fatal consequences of HIV in their home countries; the consequences of not receiving HAART was more salient for these African-origin mothers even though they now had access to it because they were living in Ireland.

#### **4.4.5 Summary of key narratives in section one**

In recounting their experiences of how these women made sense of their HIV diagnosis, it was apparent that it had been a life-changing event. For many of the women, despite the fact they may be part of high-risk groups from an epidemiological perspective, HIV was of low relevance to them prior to diagnosis. For women diagnosed before they had children it brought uncertainty to what is a natural course of events for many women. Some women were first time mothers when diagnosed. The immediate concern of mothers, at the time of diagnosis, was their children as they had to consider whether and when to test their children for HIV and these maternal responsibilities took precedence over their own emotional needs. As discussed in Chapter Two, a diagnosis in pregnancy results in the focus of care being on preventing VT and for some participants this became a preoccupation, despite the low likelihood of it happening due to the availability of HAART. This suggests that their own adjustment to being HIV positive becomes a secondary concern, demonstrating how being a mother impacts on their HIV diagnosis experience.

#### ***4.3 Section two: being a HIV positive mother***

This section presents excerpts from narratives that recount how the study participants spoke about dealing with stigma and HIV disclosure decisions, unending protection of their children from HIV stories concerning everyday life, and the support options used by participants.

### 4.3.1 Mothers managing stigma

Four mothers shared stories about how stigma featured in their lives. Sabine, who is from Eastern Europe, described how HIV stigma persists in her home country:

Sabine: Our people are more judging, you know? If someone finds out, you know, I don't think we would be so tolerant as people are here. Maybe I would experience it if I go telling everybody, but I don't.

Denise: So because you haven't told many people, it's not something that you are worried about?

Sabine: No, for me no, it is not a problem, I didn't tell I have some kind of secret.

Sabine provides insight into being a migrant with HIV and she feels that being HIV positive in her own country would be more difficult than it is in Ireland as she believes the latter is a more accepting country in which to be HIV positive. Nevertheless, she lives with a secret in order to not attract any stigmatising behaviour.

When I asked Maud, who is from Cameroon, about any experiences of stigma or discrimination, she replied:

Maud: I wouldn't say that I was. This is the only place (HIV centre) I like. Everybody knows everybody is HIV in this place, I cannot talk to anybody about it. I won't say, I won't say I have been discriminated against but maybe in the future.

This excerpt suggests that Maud expects judgement from those with whom she shares her diagnosis, demonstrating 'felt stigma' (Goffman 1986). One Irish woman spoke repeatedly during her interview about her perception of how her fear of HIV stigma affected her life. Sharon, who had been HIV positive for eleven years, explained:

Sharon: Like there's a terrible stigma about it, people do not know anything about it. I know about it, I've always known about it but people just, they think shake hands and they're going to get it. Like you're talking to them, you know, it's horrible like, society is horrible, it's cruel as well. If I hear anyone talking about it, I walk away, I don't stay in company, even my face goes red, I think oh they know. That's why I don't tell anyone. I couldn't access here (HIV centre) because it took me weeks before I rang it (laughter). Here I was 'if I go

in there I'll probably meet somebody I know', you know? That goes through me head. I just said to meself, I'll take a chance, and that's when I brought the little one in with me one day. If I go in someone will probably open that door that knows me, one of me family. I have to do it, I just have to sort me life out. I don't know it's just me, I'm probably paranoid.

Sharon's excerpt provides insight into her personal struggle with her diagnosis and her reluctance to seek support due to her fear of meeting someone she knows in the *HIV centre*. The dominant theme of her narrative is a fear of being identified as HIV positive and this has contributed to her decision not to disclose her HIV status. After eleven years Sharon finally sought help, reflected in her words 'I just have to sort me life out', which led to her attending the *HIV centre*. In addition, if any reference to HIV occurs in social conversation she avoids talking about it. Sharon admits to being paranoid about her HIV status and appears to worry that people will suspect she is HIV positive. This fear of others discovering her status was the dominant theme in her narrative and subsequent experiences of being HIV positive.

Another way stigma can feature is through the behaviour of others, even family members, and some participants spoke about this. Barbara, an Irish mother of adult children, remarked that she had to tolerate stigmatising behaviour from her adult daughter. Barbara minds her grandchildren frequently and said:

Barbara: I wouldn't now drink out of the same cup as them, use the same spoon as them, they'd all have to have different spoons. I do cut their nails but she (her daughter) doesn't let me cut the kid's nails I don't know why but she doesn't.

This excerpt indicates that Barbara tolerates certain restrictions because of her HIV status, although she admits to cutting her grandchildren's nails behind her daughters back, suggesting that on one level she defies her daughter's wishes. Certainly, it indicates that Barbara accepts a certain amount of judgement from her daughter due to her HIV status.

Within the narratives, it was also clear that many of the women were very aware of the stereotyping of those who are HIV positive. A couple of participants remarked that they were not typical of the type of women who become HIV positive. As Joanne, an Irish mother of one, comments:

Joanne: I think people mostly put HIV down to drug addicts and gay people, that's what it always was years ago, and people that sleep around. I never



slept around, do you know what I mean, it just so happened it was the first bloke I slept with that I got it off, you know, so you just can't help who you fall in love with either at the end of the day.

Joanne rejects the stereotyping of those who become HIV positive and makes it very clear that she was not sexually promiscuous, just unlucky. By saying she 'never slept around' she implies that she was aware of the social stigmatisation of those with HIV and did not feel she belonged in this group. She was from the inner city in Dublin where the incidence of HIV within the drug using population was high early in the HIV epidemic. This excerpt sees her distancing herself from this group of HIV positive people.

As an African woman, Evelyn was acutely aware of the relationship between sexual promiscuity and HIV. She revealed that she was worried that others in her African community in Ireland would blame her for contracting HIV:

Evelyn: They don't know where I got it so they think I am sleeping around and I am not able to explain to them to say it is my own husband because it is me who has it , so I can't say my husband did this to me because he had too many wives. My male or my female friends, I can't tell them, ok, and they don't suspect me because of my big butt, ok, so my big butt is covering things because usually some people that are HIV, usually some of them at home, they would be very slim, really very slim and their skin would be bad.

This quote describes Evelyn's own beliefs about those who are HIV positive and that she does not feel she fits the stereotype as she does not consider herself sexually promiscuous. Due to her large frame she feels that others would not consider her to be HIV positive as, in her opinion, those with HIV are usually very thin. Stereotyping contributes to HIV-related stigma as the judgement associated with how a person contracts HIV is reinforced by stereotyping, which in turn can contribute to how an individual feels about contracting HIV (Sayles et al. 2007).

A few participants described incidents when they had been recipients of 'actual' (Goffman 1986) HIV stigma, although most of the participants understood that they were at risk of attracting judgement from others. For the migrant mothers, the fear of judgement by others was influenced by their personal biographies and previous experiences of HIV/AIDS in their home countries. In many countries, attitudes to those who are HIV positive remain largely negative and judgmental. Sharon, an Irish citizen, shared the same concerns as the migrant mothers, however this appears to be related to her beliefs about stereotyping of those who

are HIV positive (Adedimeji 2010). Accordingly, it is evident from their narratives that stigma continues to be a concern for mothers with HIV and that they deal with it by limiting disclosure of their HIV status, rejecting HIV stereotyping, and tolerating stigmatising behaviour.

#### **4.3.2 Non-disclosure or limited disclosure of HIV diagnosis**

It emerged that telling others that they are HIV positive is a concern for the mothers and has different consequences depending on with whom the news is shared. Some had told no one outside of their health care team and those at the HIV peer support centre. Three mothers had not told their families or friends that they were HIV positive. Grace, an asylum-seeker from Cameroon, recounted that:

Grace: Not friends, nobody knows I am HIV, yes, I made one friend.

Denise: You don't talk about it?

Grace: No, when I see her I always talk about it, I have one friend who attends here (HIV centre) who we talk about it.

During this interview, Grace was quite tearful and visibly upset when she told her story. Her non-disclosure may have contributed to her feeling isolated and, in turn, low in mood as she was struggling to care for her HIV positive son who had recently come to Ireland to live with her. She was accessing some support at the *HIV centre* and her excerpt reinforces the presence of HIV related stigma even in this normalised era.

When I met Maud, she was still adjusting to the diagnosis after she had come to Ireland six months previously from Africa. She explained that she had not told anyone:

Denise: Have you told many people?

Maud: No

Denise: So who knows?

Maud: No-one, just me

Denise: Just you, that's hard

Maud: And a few friends here

Denise: So what about your family in Africa at home?

Maud: No, I can't, I can't, it is too much. I don't think I will ever tell them.

When I asked her if she had shared her diagnosis with family and friends, I was unaware that Maud had been raped by her father and had become pregnant, a revelation that emerged later in the interview. Her father had since died and this incest may have influenced her reluctance to disclose to her family. As she was also still adjusting to her diagnosis, disclosure may not have been a priority for her at that point in her life. She is getting support for the sexual assault and seems to find friends at the *HIV centre* supportive.

Telling family was also not an option for Sharon, an Irish mother of two, who had lived with HIV for eleven years when I met her. Her partner was also HIV positive and she told me why she had kept her HIV status a secret:

Sharon: I don't talk to me family, I don't get on with them, so that would make things worse (laughter), they'd run a mile. Oh no, oh no, there's a big stigma out there, I know there is, not friends or family, I know me own. Deep down I know in me own heart and soul I can't tell them, the only one I could speak to is me daughter. If I was to tell anyone it would be me daughter, I would never tell me friends or family.

After coping for so long without telling friends or family, Sharon's fear of rejection by her family has stopped her from disclosing to them. She has coped without them knowing, justifying her non-disclosure by her belief that things would be worse for her if her family were aware of her HIV status. Sharon was adamant that her family's reaction to her news would be negative. Her decision to conceal her diagnosis is the only way she felt she would not be stigmatised.

Given the potential for negative reaction to disclosure, it would appear that, for some participants, fear of rejection by their family justified their continued concealment of their HIV status. The African-origin women seemed to have concerns about their families thinking they are going to die and/or rejecting them due to their HIV status. The consequences of non-

disclosure for these participants were that it had an impact on family relationships and support options. Certainly, all participants were cognisant of the burden that disclosure can place on the recipient. For African-origin mothers, previous experiences of HIV in their own country impacted on disclosure decisions. There did not appear to be a link between the length of time a woman was living with HIV and non-disclosure, suggesting that past experiences of HIV/AIDS overpower the present, even within the current HIV normalisation era.

#### **4.3.3 Mothers' stories of sharing the news that they are HIV positive**

The remaining seven mothers have disclosed their HIV status to varying degrees. Most of them had told just family members and a few friends, and their accounts about telling others now follow. Evelyn struggled with the decision to tell her family in Africa, although her adult sons know she is HIV positive. She recounted that:

Evelyn: I had a brother, he passed away of HIV, he was HIV positive. And my sister, she is married, she has one child, but I am afraid to tell her because of her little boy at home. Sometimes, especially African people, they think if you say you are HIV positive they will start trying to say 'she's going, she's dying'. I'm afraid to tell them.

Evelyn's limited disclosure relates to her own and her family's experiences and perceptions of the fatal consequences of an HIV diagnosis. She had lost a brother to HIV and consequently did not want to burden her sister further. She feared her family's reaction to the news, as she believed they associated an HIV diagnosis with death.

Ciara, an Irish ex-drug user, told her family the day she received her diagnosis (three years prior to when we met) and they have been supportive of her:

Ciara: Yes, they all knew like when I first found out that I had it, I was really like hurt, and shocked like

Denise: Did you tell people quite quickly?

Ciara: Yes, well I told, the day I found out, like I told me Mam, and all me family knew straight away then.

Denise: And how did they respond?

Ciara: They were all heartbroken because they didn't know much about it. Like even now they still wouldn't know like a lot about it, you know, that way. Everyone, everyone I have ever told has always been real supportive and stuff.

Denise: And were you surprised at their reaction?

Ciara: No, because I would only tell people that obviously loved me.

Ciara's disclosure on the day of her diagnosis was largely beneficial for her as her family are supportive of her. She described them as 'heartbroken' and, like her, they did not appear to know much about HIV. She appears to have continued to tell others without any major adverse reactions but, importantly, only tells those who care about her, so does put some thought into disclosure decisions.

Joanne, an Irish mother of one son, comes from a large family and over the years has told most of her siblings. She explained:

Joanne: All me family know about it, like there is eleven of us, there's a lot of us, and there is twenty-six nieces and nephews. But all the nieces and nephews that are at age, they all know about it, and me brothers and sisters all know. Friends, few friends I've told, close friends I tell, you know what I mean? I wouldn't just meet somebody and tell them, but I've told a few people like. I don't tell job interviews and things like that because there's no need for them to know. But people are actually shocked when I say it to them. And that's what I say, that's what the thing is, who's to know what anyone has in this world by looking at them, you don't, so you know what I mean?

Joanne explained that some of those whom she had told were surprised that she was HIV positive, as she was not perceived as someone who would be considered at risk of contracting HIV.

Some of the migrant mothers spoke about their plans to tell their family but would have to travel home to Africa to do so. As an asylum-seeker, Elisabeth is unable to travel, but she wants to tell her mother. She told me:

Elisabeth: My family are in South Africa all back home, yes, so I wanted to tell them, but again it's something I want to do it face-to-face, yes. Because my mum is a single parent and she has diabetes, I don't want to tell her something over the phone and something that might affect her. So I want her to look at me and see I still look healthy and then tell her so she knows I am ok.

Elizabeth's desire to share the news with her mother is evident and she wants to do so in person. She is concerned as to how her mother will react to her diagnosis, as the HIV picture is different in South Africa where treatment options are not as widely available as in Ireland. It is understandable that she wants her mother to see her as a healthy person, in order to lessen the impact of the news. Elizabeth has lived with HIV since 2005 and has withheld her diagnosis from her family and, due to her migrant status, it may be some time before she has the opportunity to travel home.

Rose, an African woman living in Ireland, recounted how she deals with being HIV positive while living away from family and friends:

Rose: Yes, yes, I don't want to talk but I have to talk (laughter), kids, I wish I could lock myself in to think about this. You talk to your mum, people are dying here (in Africa), you say oh my God, me, myself, I am in this, and they don't know and you are tired of keeping this in yourself,

Rose: It's a long time

Denise: So your family at home, they don't know?

Rose: No, no

Denise: Do you feel it's something you can tell them or you would like to?

Rose: Yes, I would like to, would like to it's eating me inside, you know, alone, maybe if I share with the family, you know?

Similarly to Elizabeth, Rose would like to tell her family at home but knowing that people are dying due to AIDS at home affects her decision to disclose to those at home. She seems to want to have support from her family at home but her reluctance to tell others was intricately bound to her experiences of HIV/AIDS in Africa.

The disclosure experiences in this study were associated with both positive and negative responses. In contrast to those who had told very few, women whose families and friends knew that they were HIV positive appeared to benefit from sharing the news of their diagnosis. Disclosure resulted in increased support but resulted in mixed emotions and consequences for the participants. Within these excerpts, family and social factors appear to influence disclosure

decisions. There is no doubt that communicating such sensitive news to others is difficult (Eustace and Ilagan 2010) and whether to disclose or not did occupy mothers' thoughts as they were concerned about burdening others with the news. Face-to-face disclosure was not an option for the asylum-seeking mothers, as they could not travel because of their migration status. This concurs with findings from Ndirangu and Evans's (2009) study with HIV positive migrant women in the UK. While many had good experiences of telling their loved ones, deciding whether to tell their children brought different challenges.

#### **4.3.4 The dilemma of maternal disclosure**

A common theme across many of the narratives was the dilemma of disclosing their HIV status to their children, the majority of whom were under ten years old. Some mothers with older children, some of whom were adults, had told them, and the consequences for these women were largely positive. Three mothers, whose children were at an age at which disclosure would be acceptable, had not yet informed them of their status and their stories are presented below.

Joanne, a single Irish mother, had planned to tell her teenage son on many occasions but put it off:

Joanne: He is grand, but I still haven't told him yet, he's the only one out of me family who hasn't been told. But I'm finding that it's just getting the words out, I think he'll be alright about it because he knows about HIV, he knows all the ins and outs, he knows I volunteer in here, he doesn't know I come in here as a member because he doesn't know about the virus. But you see he only done his Junior Cert (O levels) last year and I didn't want to, you know, come out and say it then but because he's fifteen and he's gay he needs to know about HIV, so I have to tell him soon, kind of thing, but it's just I am nervous of telling him.

Denise: And is that something that you've been thinking about for a long time?

Joanne: I've always wanted to say it to him, always wanted to say it, but as I say, I always wanted him to be a child as well. So I never gave him any worries or I didn't want him to be worried about anything in his life because to me kids should be kids, a lot of kids grow up too quick nowadays so I was trying to keep everything, you know, from him. But as I said, he's a teenager now so he needs to know about safe sex and what diseases are out there and stuff like that. I think if he finds out that his mother and his father has it, it'll hit home a

lot more, you know what I mean, he'll practice safer sex a lot more, I know it's a scary, very scary tactic, but it's the truth, I suppose.

Joanne has devoted considerable thought to the timing of disclosure to her son. Her struggle with the decision is evident, and she has always found reasons not to tell him. In this instance, disclosure is complicated because she would also be disclosing that his father is HIV positive. Additionally, Joanne feels she needs to be careful about how to tell him because as a young gay man the news will have an added dimension. Her lack of disclosure is largely due to her desire to protect her son and to ensure that he has a normal childhood.

As noted earlier, Sharon, an Irish mother of two, has not disclosed to any family members or friends. She explained why she had not told her adult daughter:

Denise: Do you think it's something you should do at some stage?

Sharon: I actually want to do it because she is twenty-four this year and I do say to meself if anything happens to me, like I don't know

Denise: Is she close to your younger daughter?

Sharon: Ah yes the two of them have a great bond, because I'm always saying if anything happens to me you look after her, don't let anybody take her, you know, like the little one loves her.

Denise: Do you think she might even suspect something?

Sharon: No, I hide everything, I just, everything was just hidden away with her, even when I found out I had it I was giving her certain towels to use, that's how stupid I was like, I was terrible like, it was just me, just crazy.

Denise: What are you afraid of when you do tell her, what is stopping you?

Sharon: I'll tell you, she'll probably blame me partner on it. Yes, she knows like he's an ex drug addict and he was very young because she'd often hear his family talk about it because I've never told her. But she used to say to me like, and I'd say 'that was years ago when he was young, he's changed his life around', but I know she'd turn on him straight away because she's that type of person.



Denise: Are they close?

Sharon: She gets on great with him, she loves him, he's like a father figure to her. Yes, I suppose there is an awful lot there so that is one, yes that is one of the reasons I don't want to hurt her.

Denise: Do you ever think she could help you, she could support you through it?

Sharon: And then I'd say to meself then I'd have an awful lot of pressure on her life, she has to have her own life, yes, I don't want to be putting pressure on her neither.

Sharon's overall difficulty in dealing with her diagnosis appears to contribute to her concealment of her HIV status. The narrative is a stark description of her non-disclosure decision and her attempt to make sense of it. She acknowledges her fear of the possible negative consequences of disclosure for her daughter's relationship with her stepfather. Her lack of disclosure is related to her desire to protect her daughter and allow her to live her own life. As Sharon has had no experience of telling others, she may be assuming incorrectly that it will have negative consequences for her family and herself when, in fact, it could perhaps be beneficial to her.

Another mother, Rose, who is an African migrant with three children including a son in his early twenties, had not yet told her son:

Rose: I will tell the big boy, the twenty-two year old, but leave the two little one's for now, oh yes, they are too young. Yes, I will make him safe as well. I'm keeping him safe as well.

The primary motivation underlying Rose's desire to disclose to her older son is protection. She wants to protect him from infection. However, she did not appear to have a particular plan for disclosure, despite the fact he is now an adult. These mothers make sense of non-disclosure by linking it to a desire to protect and to avoid burdening their children and this does not appear to be related to their children's ages. They all intended to disclose at some point. What is clear in these excerpts is that they had thought a lot about disclosure and that, for some, the task of telling their children was fraught with anxiety. This is evident in the manner in which they

articulated their feelings about disclosure. Joanne's use of the expression 'kids should be kids' encapsulates a shared belief that it was best to delay disclosure to their children.

None of the mothers of younger children had disclosed to them as it was a task for the future. However, most of them envisaged a time when disclosure would be necessary and they all indicated their intention to disclose when their children were older. Elisabeth, an African mother of two girls, has plans to tell her daughters:

Elisabeth: Yes, I've spoken to my partner about it and then he was like 'you should leave it for now until they are old enough, when they are old enough we tell them'.

It is evident that the ages of Elisabeth's children and her partner's feelings have influenced her disclosure plans. Her partner is also HIV positive and the father of her younger daughter. She expressed an intention to tell them at some point in the future.

Ciara, an Irish mother, spoke about why she does not want to tell her six-year-old daughter at the moment:

Ciara: No, I don't know like, I have thought when will I but I'd never want to hurt her like, I wouldn't want to worry her, you know, that way, yes.

Denise: Does she ever ask about the medication, the tablets, or does she notice that?

Ciara: Yes, she would notice me taking the tablets, she sleeps in a room with me because I run a women's shelter. She lives with me there, so she would see me taking it but like I just say like me vitamins or something like that.

Here Ciara's lack of disclosure is because she wishes to protect her daughter from unnecessary worry. This belief concurs with the reasons for non-disclosure by the mothers of older children. Ciara had told her daughter that her HIV tablets are vitamins because she feels her daughter is too young to know about the diagnosis.

Disclosure is also a future decision for Kate who has two young sons. She has normalised the act of taking tablets as a way of dealing with potential questions from her sons. She reveals that her children asked her:

Kate: They ask “Why do you take drugs?” And I'd say well a lot of older people do so at the moment, it's a lot of older people do take medicine and I do take more than some people and I don't have very strong blood and I don't have very strong bone's. I think in time if it becomes more necessary, the boys take their little vitamins and then they would say to me “did you take your vitamins or your medicine?” I think in time if it (disclosure) becomes more necessary, I will.

By normalising daily medication, Kate is also preparing her children for future disclosure. She has told them that she does not have “very strong blood” and as such is managing disclosure by gradually imparting information. Additionally, these excerpts suggest that, on one level, these mothers have embraced normalisation in how they think about their health concerns as taking medication is part of self-care and many people take tablets daily.

These findings are consistent with previous research reviewed in the literature review, emphasising the complexity of disclosure and that mothers living with HIV struggle with it (Hunter 2009), and many delay telling their children for as long as possible (Hawk 2007). Their assumption that maternal disclosure will be detrimental to their children contributes to their reluctance to tell, and this may be unfounded in some circumstances as there can be benefits to children knowing their mother's HIV status (Delaney, Serovich and Lim 2008), particularly for families with older children (Hawk 2007).

#### **4.3.5 Continuing to protect children**

Some participants talked about the possibility that they could potentially infect their older HIV negative children, despite the low likelihood of it happening. Rose told me about an incident when she cut her finger:

Rose: One time I hurt myself. Instead of sitting down and having a cup of tea and a rest, I took a mop straight away to the kitchen, I took a mop from the shed, take the high heels off, take a mop and clean. Why did I do that? I don't know. I don't want a dirty house as well, and then I squeezed the mop and broke a nail and the blood, even though I was at home I was scared. I said (to children) “no, no, don't come next to this”. The blood was flowing, flowing, it was very painful but my fear was the blood, “don't come next to me”. But I made sure that nobody comes downstairs, “stay upstairs with your big brother, I don't want anybody near this blood”. I always train them that way, blood, when they see blood they run, because I trained them that way because I am scared, I'm still scared.

Rose's imagery and wording in this vignette provide insight into how she deals with a normal domestic accident. She spoke quite quickly while telling me about this incident and a sense of panic was palpable in her description of what happened when she cut herself. Her hyper-vigilance about cleaning to prevent her children from being exposed to HIV-infected blood indicates that Rose lives with this anxiety. She had warned her children about not having contact with her blood, as she appeared worried about possible contagion through a blood spill. Rose's vivid narrative reveals that, for some mothers, protecting their children from HIV is an enduring process. Two mothers mentioned specific measures that they have taken to ensure their children are not exposed to HIV infected blood. Ciara, an Irish mother of one, pointed out the steps she takes to avoid contagion:

Ciara: Obviously, I'm just careful like with toothbrushes, razors, and stuff like that.

Likewise Maud, an African mother with a young daughter, spoke about this:

Maud: You know at home I just have to be very, very careful with razors, with everything, extremely careful. That is another fear I have, sometimes you scratch yourself and you don't know, and that's the greatest fear I have.

Denise: But you understand the chances of infecting her are very small?

Maud: Yes, but maybe I get a cut and she got a cut, that is my fear.

It is worth noting that Maud, like Rose, was influenced by previous knowledge of HIV in Africa as a feared fatal illness. For Maud, the fear of infecting her daughter drove her to take extra precautions, suggesting that although knowing that the risk of contagion is small, it is not enough to ameliorate concerns when one's own child is involved.

As a grandmother, Barbara, an Irish mother of three adult children, also had concerns about the possibility of her young grandchildren being exposed to infected blood. She recounted:

Barbara: I used to get paranoid meself because I wouldn't drink out of their cups when my grandkids come over. Now I give them their own cups, their own spoons and all that because I didn't know any better until I got to learn in here (HIV Centre). They told me you don't get this and you don't get that. And then if I got cut, I remember me finger got cut and the blood went out, and she (granddaughter) got marked, you know, and I said "oh my God".

Barbara's narrative reveals the steps she has taken to ensure that her grandchildren do not come into contact with HIV, reflecting the common myth within society that it is a highly contagious condition. This is within an Irish context where HIV has not been lived with as a national crisis fatally affecting every family, as some of the African-origin mothers would have experienced. Barbara, nevertheless, seemed to be dealing with 'hidden stigma' from her own family who appear uncertain about the infectiousness of HIV. She seems to be trying to deal with her daughter's concerns as best she can while maintaining access to her grandchildren.

The on-going protection of children from HIV by mothers living with HIV may be a surprising finding due to the low likelihood of transmission. Earlier pre-HAART research, as discussed in Chapter Two, documented the steps mothers living with HIV take to protect their children (Ingram and Hutchinson 2000, 1999). These steps included being hyper-vigilant in the home to ensure there was no possibility of contact with infected blood. More recently, the mothers in Walulu's (2007) study reported being very conscious about cleaning and avoiding blood contact in the home, in order to ensure that HIV negative children remained safe. This fear of contagion may be irrational but these narratives show that it is part of the daily challenge for some participants in this study, and appears to relate to previous histories of HIV. The risk of potentially infecting their children with HIV concerned them, even though this protectiveness could be interpreted as irrational. Their protectiveness was, in a way, not justified by the levels of risk in each case or by histories of transmission with which the women were familiar but it remained a concern for these women.

#### **4.3.6 Everyday life**

Within the narratives, the mothers spoke about how they dealt with life as HIV positive mother. Joanne, an Irish single mother, revealed that she coped with being HIV positive by maintaining a positive attitude:

Joanne: I think positive, that's why I never got sick, you know what I mean, because I have it, I never thought this is going to kill me or I'm going to be really sick from this.

Denise: So you don't think that you may die early because of HIV?

Joanne: Come here, cancer runs in me family, aneurisms run in the family, madness runs in the family, Parkinson's disease, there is a whole lot of things

out there that run in my family on both sides. I'm more likely to get one of them (laughter), I've more chance to run out there and get a smack of a bus than dying of HIV, that's the way I see it. You know what I mean? I think my positive attitude has helped me to not be sick and live longer. Well I've always believed that, you know what I mean, if you're given a death sentence and you take it as a death sentence and you are going to die, you just give up. Most people just give up when they're told things like that.

Joanne maintains that her attitude to HIV may have contributed to her good health and she does not believe she will die from HIV. She also refers to illnesses that run in her family and that she is more likely to get one of them or be hit by a bus rather than die from HIV. This attitude may be due to her remaining asymptomatic since diagnosis.

Likewise, Elisabeth, an African asylum-seeker, felt that her positive attitude and sense of spirituality has helped her as an HIV positive individual:

Elisabeth: What works for me, ah I don't know, love yes, laugh, laugh, like don't take things too seriously, you know, and just try to keep my spirits high, yes, by listening to gospel music, I love to sing.

Denise: Very good, (laughter) and do you find because you have children that makes you different?

Elisabeth: Yes, I have to be strong for them so, you know, even if the situation is bad I have to try and find some humour in my life, something funny about it, because I can't afford to be stressed. I have to think, so that's what I try to do.

Denise: And would you have been different before HIV or is this how you are anyway, do you think?

Elisabeth: Personality, personality-wise yes, but then I think, yes, things would be different, yes, because now I take life seriously, yes, but before not really, but now I take life seriously, and I wake up every day and I say thank you, you know, because everything is a blessing, ok so, yes, yes,

Denise: So obviously your religion, your spiritually is quite important?

Elisabeth: Sometimes I get angry with God but that's understandable, but I do.

Denise: Why do you get angry?

Elisabeth: Because when things get really bad and you look left and you look right and there is no help and you just don't know what to do and then it's like God where are you (laugh), so then I get angry and then I get over it and then I'm like I'm sorry (laughter).

In this excerpt, Elisabeth describes how her attitude to life helps her deal with being HIV positive, while acknowledging that HIV has impacted on her as she now takes life more seriously. For her, motherhood and diagnosis co-occurred as she received her diagnosis late in her first pregnancy. She finds comfort in her spiritual beliefs and admits to getting angry with God at times for the situation she finds herself in. Elisabeth appears to cope well with her HIV, despite having to deal with the lengthy asylum-seeking process and the restrictions placed on her and her children. These findings concur with two UK studies with migrant African women that reported an increased sense of spirituality following diagnosis (Doyal and Anderson 2005) and similarly, Dibb and Kamalash (2008) found evidence of positive adjustment and coping after diagnosis.

Another coping strategy described by certain participants was that they tried to minimise the effect of HIV on their children and family life. The women talked about striving for a sense of normality as they perceive themselves as 'normal', suggesting that being HIV positive does not define them. Kate described herself as:

Kate: I'm the same as everybody else now (as a mother), I suppose, as every other woman, I felt so separate before even though there are many women who don't have children but I think the fact that I have had them makes me the same. I'm stronger, I have a much stronger sense of myself as a mother, I suppose I always was a nurturer.

Kate appears to have a strong maternal identity, her narrative tone is progressive. She sees the benefits of being a mother despite the other challenges she faces due to her HIV status. She revealed earlier that she did not think she would live very long when she was originally diagnosed over twenty years ago. Becoming a mother was very important to her and she now sees herself as the same as other mothers, despite her HIV status. Other researchers have also reported the importance of the maternal role to HIV positive women (Cibulka 2007, Barnes and Murphy 2009, Doyal and Anderson 2005, Sandelowski and Barroso 2003b).

There are similarities between Kate's attitude and that of Elisabeth despite their very different personal histories. Elisabeth tries not to let HIV dominate her life by minimising HIV in everyday life. As an asylum-seeker, she has many issues to contend with, including HIV:

Elisabeth: For myself, I just told myself that I don't want to think about me being HIV positive. I want to live my life, how can I put it, and not say 'I can't do that because I am HIV positive', so I tend not to think about it, I know I'm going to be there for my kids. I'm going to take my meds and be healthy, and I am going to get education and better my life and look after my children, so I still have that positive future.

Elisabeth explains that her approach to life is to minimise the impact of HIV and to comply with her medication. She has plans for her and her children's futures so is motivated to care for herself because of her maternal responsibilities. She also appears to have deliberately adopted a positive attitude to managing her life as an HIV positive individual. Ciara, an Irish mother of one, has adopted a similar attitude:

Ciara: I don't really think about it a lot, like you know, it's not something I dwell on or, you know, I just kind of get on with it like, I can't change it now.

In not thinking about being HIV positive, Ciara demonstrates what Anderson and colleagues (2009) describe as "submersion" of HIV. This allows Ciara to get on with her life while acknowledging that it cannot be changed. Other participants adopted a similar stance. Sabine, who is from Eastern Europe, has been living with HIV for three years:

Sabine: I see myself as a normal person, you know, as normal. I don't see because I have it I'm some kind of, you know, other people has to pity me. I want to be normal, I want to live life like a normal person, and it's the same like any other mother, you know?

Sabine describes herself as normal and the same as any other mother. Becoming a mother allowed her to see herself as a normal person. She does not want to be pitied, even if her maternal experience has been different from that of unaffected mothers, and as a woman diagnosed in the HIV normalisation era, Sabine has hope for a normal future with her child.

These narratives suggest that the reality of life as a mother with HIV involves a variety of ways of living. Some mothers live by maintaining normality and having a positive attitude, while other approaches include not thinking about it, minimising the effect of HIV and normalising



the routine of taking tablets. Previous research has reported similar findings (McDonald 2008, Cibulka 2007, 2006). Some of these mothers are also dealing with immigration issues that bring a lot of uncertainty and restrictions into their lives. Ndirangu and Evans (2009) suggest that because asylum-seeking HIV positive women have to deal with HIV while adjusting to life in a new country, this can bring added pressure to their lives.

#### **4.3.7 Stories of support**

The narratives indicated that the main sources of social support were family, friends and peers. Mothers who had shared their diagnosis with family described benefiting from the resulting support and practical help. Ciara, an Irish mother of one, recounted that her family were supportive.

Ciara: Everyone I have ever told has always been real supportive.

Joanne, an Irish mother of one son, said that all of her family knew she was HIV positive and she finds it supportive:

Joanne: All me family know about it and a few friends I've told have been great about it.

Support from other HIV positive people emerged as another important way of dealing with life as a HIV positive mother. All participants were members of an HIV support centre and five mothers described how they have benefited from attending there and their reasons for continuing to attend. Some were unsure as to what to expect when they first visited. Evelyn, an African mother with adult children, revealed that she had been reluctant to go initially:

Evelyn: You know, before I didn't want to come here (HIV centre) but the social welfare in the hospital, she is the one who said "I think you are too lonely, you think too much", because I am always indoors closing windows and everything and I don't see anybody, but then I discover I have a second house, meaning here, I am comfortable. I am very, very, very, comfortable here, and it's really confidential and, you know, no- one minds anybody else's business here, because we talk to each other, we would be in the same boat.

The benefits of attending the *HIV centre* are evident in Evelyn's story. She says she is comfortable there and refers to it as a 'second home' despite her initial reluctance to attend.

Meeting and talking to other HIV positive people helps her, as she lacks support from her own family who are in Africa.

Joanne's experience of attending the *HIV centre* is similar to Evelyn's in that she feels a sense of belonging there:

Joanne: Everyone is in the same boat here. Well, so some people are different, some people have Hepatitis as well as HIV, other people have drug problems, so that relates to their HIV as well, and there's loads of different things, everyone's the same here, everyone, no matter what.

Denise: And do you like that, do you find that supportive?

Joanne: Yes, I think that's the best thing about coming in here, it's because everyone has the same, nobody is any different from anybody else no matter where you are from.

This quote demonstrates the importance of meeting others in the same position and Joanne's use of the expression 'everyone is in the same boat' provides insight into the isolation of being HIV positive. Joanne receives a lot of support from her family but she still acknowledges the benefit of an environment where there is an acceptance of HIV. Because of the risk of potential stigma associated with HIV, limited opportunities exist to meet with other people living with HIV and the next excerpt describes the value of meeting others with HIV. Sharon had been attending the centre for about six months when we met. She described her reason for attending:

Sharon: Why I came here because it was last year, like I was thinking about it a lot but I had no-one, like that, no one knows anything, they don't know what's wrong with you. You want to talk to someone but you're afraid, you can't trust them and that's when I ended up coming here. I just says to meself you have to do it. I wouldn't tell anyone that I'm positive, like I wouldn't turn around and say to one of the women here I'm HIV positive, I just sit there. I couldn't believe it, they're just saying 'I'm HIV positive' and here I was, oh my God, this is all new to me.

As noted earlier, Sharon had not disclosed her HIV status to her family and friends since her diagnosis eleven years ago and accordingly had very limited support mechanisms. She appears to find attending the centre beneficial even though she remains on the periphery of activities. Sharon was surprised at the openness of some of the other women around their diagnosis, as

she did not feel comfortable identifying herself as an HIV positive woman. In contrast to Sharon, Maud came to the centre shortly after she received her diagnosis:

Maud: They referred me here because I had nobody to talk to, actually. But when I came, I don't know, they lifted something off my shoulder. They had to persuade me, this woman who comes talked me into coming here, that it would be good for me, that I will get to meet the same people like myself. I just summoned up courage one time and came in and I was a little shocked because everyone was happy and doing their thing.

Denise: Were you surprised?

Maud: I was very surprised because I don't know, but I was surprised.

Denise: That you can be happy with HIV?

Maud: Happy, I can talk freely with people

Denise: So do you come here a lot now?

Maud: Yes, I come here all the time.

Denise: How often?

Maud: Some weeks I come sometimes three times, or sometimes I come once a week, yes, because of my daughter as well, I can't get somebody to look after her.

Maud, a newly diagnosed woman, revealed that a weight was lifted from her when she attended the centre for the first time. This segment describes how accessing support in the centre showed her that people could adjust to life with HIV. She, in turn, availed of the opportunity to talk openly about her diagnosis and her excerpt suggests that she benefits from meeting others who are HIV positive in a safe environment. Rose, an African mother of three, also told me about her first visit:

Rose: Oh my God how can I put it? Just the atmosphere, the warmth, I just felt not at home but sort of, and, you know, maybe it was because people who were here are HIV positive, so I think I felt a sense of belonging ok. People are very friendly like, and I've just started a volunteering job, just to keep my mind

busy as well, yes and to keep me young of course (laughter), the people are very friendly and very helpful as well. I come maybe twice a week, ok, because I live far away.

Rose's account stresses the importance of the sense of belonging when she originally went to the centre. Identifying quickly with others who were HIV positive was useful for her and she felt warmth and at home there. This sense of belonging contributed to her feelings of support while there.

These descriptions about attending the *HIV centre* reveal that some of the women were a little wary of going there initially, although most of them found it useful to meet others who were living with HIV, particularly those with limited support, suggesting that they experienced 'bonding social capital' (Putman 1995). Overall, their stories showed the value of meeting peers and other researchers have reported this phenomenon previously (Walulu 2011, Veinot 2010, Walulu and Gill, 2011, Walulu 2007). Attendance at the *HIV centre* helped them to accept their diagnosis, gave them a sense of belonging and reduced their feelings of isolation and lessened the related psychosocial effects (Walsh et al. 2012).

#### **4.3.8 Summary of key narratives in section two.**

In this section, the psychosocial issues faced by participants were presented. In recounting their experiences, the mothers in this study spoke about the impact of living with HIV and how they perceived themselves in relation to contemporary HIV construction. The risk of stigma was real for some mothers and was interlinked with disclosure decisions. An important finding was that the complexity of disclosure persists in the post-HAART era. Some participants have chosen to tell very few, despite having lived with HIV for some time. For non-disclosing mothers, the consequences of limited disclosure are tough. Decisions about how and when to tell children was explored in some of their stories. Non-disclosure to older children appeared to be related to their desire not to upset or burden them with the news. Their accounts showed that attending the HIV centre helped them to accept their diagnosis, reduced the isolation they felt and allowed them to develop enduring friendships. Relationships with other HIV positive women were significant, contributing to a sense of wellbeing.

#### **4.4 Conclusion**

In this Chapter, the study findings reveal a variety of experiences about being a MLH and demonstrate how being HIV positive influences the maternal experience of the study participants. The next Chapter discusses how the findings relate to theory, to establish the contribution of this study to the body of knowledge on living with HIV.

## ***Chapter Five: Discussion***

### **5.1 Introduction**

This Chapter discusses my interpretations of the narrative findings within the theoretical context of previous research, in order to provide a greater understanding of the lives of mothers living with HIV. The prevention of HIV transmission between mothers and babies, and the reproductive decisions facing HIV positive women are significant themes in the HIV literature; however, there is a paucity of research focusing on the subjective experiences of mothers living with HIV. This original study explores the experiences of Irish based HIV positive mothers and reveals that all participants heavily invested in their mothering role and this investment is central to their lives. To recap, the study sample included eleven mothers and they had twenty-one children between them of whom the age range was from adult to toddlers. Only one mother had an HIV positive child. Seven were mothers when diagnosed, two were mothers-to-be and two women did not have any children at diagnosis. Five women had children after their diagnosis and three of them were pregnant for the first time. In total, following diagnosis these women experienced seven pregnancies between them. Section one considers the meaning and impact of an HIV diagnosis with particular emphasis on the pregnancy experience and section two discusses psychosocial impacts of being an HIV positive mother.

### ***5.2 Section one: The meaning and impact of an HIV diagnosis***

This section presents two key aspects from the narratives, the HIV diagnosis and the experience of being a pregnant HIV positive woman, aspects that illustrate the meaning of the diagnosis for the study participants.

#### **5.2.1 Why an HIV test?**

A variety of circumstances led to the women undergoing an HIV blood test, including antenatal testing and health screening for newly arrived asylum-seekers. Most participants did not believe they were at risk of HIV infection prior to their diagnosis, as they did not feel that they fitted the stereotypical profile of those who become HIV positive. However, prior to diagnosis a number of the women had a previous or current partner who was infected. Some of the

participants had come from countries with high incidence of HIV disease, others had been or currently were in a relationship with a man who came from a country with a high incidence of HIV and some were in relationships with men who, regardless of country of origin, has only been recently diagnosed. This denial of risk prior to diagnosis is consistent with previous research with HIV positive migrant women (Ndirangu and Evans, 2009, Doyal and Anderson, 2005) and studies with newly diagnosed women (Walsh et al. 2012, Stevens and Hildebrandt 2006). The African-origin participants may have thought that they had left the risk of HIV behind in their home countries, yet all but one had received their diagnosis in Ireland. The unexpectedness of an HIV diagnosis for these mothers was due to their perception that they did not fit the profile of those who become HIV positive and so were not at risk of HIV infection. This suggests that prior to diagnosis most participants saw HIV as something that happens to 'others' (Joffe, 1999 cited in Belton 2011). Walsh and colleagues (2012) argued that the readiness of a woman for an HIV positive result influences her reaction to the news. This study's accounts confirm that many participants were shocked and unready for the result despite contextual risks factors such as their country of origin, country of origin of their sexual partner or being in relationships with known HIV positive men which resulted in serious consequences for their health.

### **5.2.2 Receiving an HIV positive result, a child-centred response**

Some participants shared vivid descriptions of when they were diagnosed despite the fact that for some it had been many years ago, indicating that it was a salient life event. Within the narratives, an HIV diagnosis occurred at different points on the mothering trajectory. The majority of participants were either already a mother or pregnant when diagnosed HIV positive. Previous research has considered either women's diagnostic experiences or how pregnant women deal with an antenatal HIV positive result (Walsh et al. 2012, Kelly 2012, Kelly, Alderice, and Lohan 2009, Long 2009, MacDonald 2008). In the current study, a significant shared experience for the mothers at diagnosis was a heightened sense of responsibility towards their children, both born and unborn. In particular, participants' primary concern upon diagnosis was the possibility that their children could also be HIV positive, and very few spoke about their own personal needs following diagnosis. Children born prior to diagnosis would not have had access to vertical transmission interventions, therefore their children's HIV status is of major concern to newly diagnosed mothers who suspect they could have been HIV positive when pregnant. Consequently, until her child's HIV status is

established, a mother has to deal with the fact that she could have unwittingly infected her child. Nevertheless, the risk of vertical transmission is dependent on the point of infection and older children would not be at risk of being infected if their mother had contracted HIV after they were born. While earlier research examined HIV testing of new-borns (Shannon and Lee, 2008), limited information exists on maternal experiences of testing older children for HIV. This study found that, upon diagnosis, mothers prioritised viral testing of their children, irrespective of the point of infection.

Women infected with HIV after their children were born still wanted to have them tested. This is unsurprising, given that BHIVA guidelines (2009) recommend that "...all the children of HIV positive parents are tested for HIV"(p. 19). Therefore, doctors advise all newly diagnosed mothers to test all of their children, which is a causal factor in them prioritising this testing as soon as possible after diagnosis. The mothers of children who were born prior to maternal infection occurring appeared to overestimate the possibility of their children being infected, this may be related to the advice given by doctors upon diagnosis. The study findings suggest that, even when the likelihood of VT is low mothers were troubled about the possibility that they could have infected their children.

Previous recent research has reported that for HIV positive mothers their own health is of less importance than that of their children (Walsh et al. 2012, Walulu, 2011). The current study affirms and extends this notion of 'child-centeredness'. These narratives suggest that 'child-centredness' occurs at the critical moment of diagnosis and represents a 'moment of being frozen in time' that cannot be overcome until the status of their children is known, only at that point can the mother look past the 'child-centredness' to consider her own response to the news. There were similarities between participants who were already mothers and women diagnosed due to antenatal testing at the moment of diagnosis in so far as the latter equally spoke about the dominance of their concerns about the possibility VT. Whilst the 'moment of being frozen in time' perception is similar, in fact the risk is profoundly different between mothers and pregnant women. Pregnant women have to take HAART to reduce the possibility of infecting their unborn babies and the outcome of this intervention is not be known until after their baby is born. This dilemma is resolved sooner for mothers, usually within a couple of months of diagnosis, than for pregnant women.

A number of studies have proposed that the pregnant woman's dominant concern following an antenatal diagnosis is the prevention of VT (McDonald 2008, Kelly and colleagues, 2012, Kelly,



Alderdice and Lohan 2009, Long 2009, 2006). This study highlights that the shared reaction of those who are already mothers and pregnant women is similar and focuses on possibility of vertical transmission having occurred. However it also distinguishes that the issue is resolved relatively soon for mothers after diagnosis, whereas mothers- to-be need to wait until at least three months after the birth of their baby to bring this to a conclusion.

A distinctive feature of this study was that some of the participants had been diagnosed during their first pregnancy. This timing of an HIV diagnosis complicated their transition to motherhood; this unique situation has received little attention previously. Participants who were first time mothers-to-be when diagnosed did not have previous pregnancy experiences and knowledge to draw on. These mothers-to-be had to simultaneously deal with the normal first time pregnancy anxieties along with the associated implications of their HIV diagnosis, a situation that could perhaps overshadow the joy and anticipation associated with first time motherhood.

Following their diagnosis, some women describe adjusting their life expectations, for example one woman actively avoided intimate relationships since her diagnosis in the mid-1990s, and others changed or abandoned career plans, indicating a level of biographical disruption (Bury 2001, 1991, 1982). Certainly, the study's asylum-seeking mothers diagnosed in Ireland did not anticipate that HIV would be part of their future when they embarked on their migration journey. Supporting this, Crossley (2000) argues that an HIV diagnosis affects individuals' temporal orientations due to the fact that many live life by looking to the future. As discussed in Chapter Four, participants' diagnostic experiences spanned twenty years, consequently some had been diagnosed when HIV was a life-threatening illness whereas others were diagnosed during the HAART era. Therefore, some spoke of amending their future plans when first diagnosed, however, over time, their plans had changed as the benefits of HAART became apparent on the life expectancy of those living with HIV.

This study's findings indicate that an HIV diagnosis affects the outlook of mothers living with HIV although, over time, the impact is not necessarily always negative, indeed, it can be a motivator for positive change. For example, one participant successfully underwent detoxification from opiates after becoming HIV positive, despite previous failed attempts indicating her diagnosis motivated her to finally address her addiction problem. Others ended dysfunctional relationships some of which had been with the men who infected them with HIV. This idea of an HIV diagnosis as a motivator for positive change is consistent with other

research findings (Wilson 2007, Doyal and Anderson 2005, Pittiglio and Hough 2003).

Therefore, these findings extend understanding about how mothers respond to and manage an HIV diagnosis.

O'Reilly (2008) argues that one of the components of feminist mothering is agency, which is the ability to make choices and changes within one's life. Following diagnosis, some mothers demonstrated agency as part of the changes they made in their lives, suggesting that their diagnosis contributed to this. However, for newly diagnosed mothers-to-be the potential for agency is limited, as until their babies are born to know whether their children are HIV positive or not. Therefore, the role agency has in the lives of newly diagnosed mothers-to-be appears to be related to the diagnosis context.

This study provides insight into the meaning of an HIV diagnosis for mothers. For some the transition to motherhood coincided with the diagnosis, due to antenatal screening, whilst for others they were already mothers. To summarise women diagnosed as mothers, or mothers – to- be appear to be more concerned with the possible ramifications of the diagnosis for their unborn babies and children than with their own personal needs. Their need to know if their children are HIV positive too is their priority after diagnosis. Given the participants' descriptions of the process of diagnosis and the significance they placed on the diagnostic encounter, it is important that the impact of an HIV diagnosis is recognised for mothers. Their HIV diagnosis caused some mothers to make significant life changes. Much prior research has focused on diagnosis in pregnancy whereas this study explores diagnosis across the mothering trajectory, including first-time mothers. My research therefore builds on previous work to give insight into the meaning of the maternal HIV diagnosis experience.

### **5.2.3 Pregnancy experiences when HIV positive**

During their pregnancies all participants had access to antiretrovirals. Some participants did not talk about their pregnancies in any great detail; others talked about how their first pregnancy coincided with their HIV diagnosis; two spoke about being diagnosed very late in their pregnancies; and others became pregnant after diagnosis. However, the experience of being an HIV pregnant woman differs substantially from non-affected women due to a risk of vertical transmission.

As previously indicated in the literature review Chapter, reproductive/pregnancy decisions are magnified for HIV positive women. It is somewhat surprising that women who became pregnant after diagnosis and women diagnosed antenatally shared similar concerns about the possibility of VT. One might be forgiven for assuming that women who know themselves to be HIV positive would have more faith in the effectiveness of the interventions as a result of their knowledge and experience of HIV and its associated medications. But yet this study found that both these groups shared equal levels of anxiety and fear of VT. In some cases, despite reassurance from their doctors, participants held an exaggerated sense of the risk of infecting their babies while pregnant which is likely to be due to these women prioritising their children's welfare over the own.

It was also apparent that the participants' individual personal biographies played a role in shaping their attitudes to accessing HAART as a VT preventive measure. Some of the African-origin women recounted a belief that, in their home countries, it could be difficult to get antiretrovirals, indicating that they had a heightened awareness of the consequences of not having access to HAART when pregnant. These women valued access to HAART and had trust in its effectiveness to prevent VT. Their personal biographies and their previous exposure to the fatal effects of HIV contributed to this increased awareness and many of them spoke of their relief that HAART was accessible to them in Ireland.

Additionally, participants spoke about a high sense of medicalisation of their pregnancies due to the risk of perinatal infection. HIV care during pregnancy is focused on the prevention of new infections and these narratives indicate that during pregnancy HIV positive women cannot be separated from their children as biomedical subjects. During pregnancy these women are considered as a 'disease' and not a person (Rose 2007) as the priority of care is to prevent vertical transmission. It is clear that preventing VT is a central component of an HIV positive woman's pregnancy experience. Most pregnancy orientated HIV research has focused on the prevention of vertical transmission and only a limited amount has explored the subjective experiences of HIV positive pregnant women (Kelly et al 2012, McDonald 2011). However, this study affirms that pregnancy is a highly emotionally charged time for HIV positive women due to the burden of anxiety surrounding the risk of VT despite medical assurance of its efficacy. Therefore, these narratives offer insight into social meanings attached to the process of preventing vertical transmission during pregnancy, in contrast to the dominant medical research focus on the prevention of VT per se. Having considered the diagnostic and

pregnancy experiences the next section now examines the psychosocial concerns that featured in the participants' narratives.

### ***5.3 Section two: Psychosocial impact of being a HIV positive mother***

This section focuses on psychosocial aspects of being HIV positive, particularly stigma and disclosure. For these mothers, stigma plays a role in the management of information relating to their diagnosis. In this section, strategies that participants use in managing HIV, the importance of peer support, and the on-going effort of protecting children are presented.

#### **5.3.1 Mothers managing stigma**

Participants' narratives revealed an awareness that being HIV positive can attract judgement from others, and stigma emerged as a concern for most of them. Goffman (1986) identifies stigma as both an individual and a social process. Three specific identifiers of HIV stigma were evident in this study's narratives: participants described tolerating stigmatising behaviour from relatives and friends; dealing with HIV stereotyping and internalising a sense of being devalued.

Herek (2002) posits that HIV positive individuals awareness of non HIV persons assumptions that the condition can be contracted through social interaction led them to accept and go along with certain restrictions that may be imposed on them in social settings, for example, the use of separate cutlery for the HIV positive person at a social gathering in an individual's house. In this study, participants spoke about tolerating stigmatising behaviour for the sake of family relationships and their children. Herek's (2002) work focuses on individual HIV experiences and does not take into account how being a mother adds another dimension to HIV-related stigma. This acceptance of judgement from relatives supports previous research, suggesting that HIV positive women live with a sense of being devalued because of their status (Mc Donald 2008, Steward et al. 2008, and Campbell et al. 2007). The process of mothers being treated differently by their family and friends, also known as 'othering' (Campbell, et al. 2007), reinforces the internalisation of a sense of being devalued. The narratives also record that some of these mothers lived with a sense of being devalued even if they had not actually been discriminated against. Critically, this reveals evidence of the continued marginalisation and 'discrediting' (Goffman 1986) of mothers living with HIV in this apparent era of HIV normalisation as just a chronic illness. If there are notions that normalisation has given way to reduced HIV-related stigma, some of this study's narratives indicate the contrary.

Most participants were conscious of the negative stereotyping attached to HIV positive women, even in this era of HIV normalisation. Indeed, during the interviews many adamantly distanced themselves from HIV associated stereotypical behaviours. While one Irish participant admitted she had a drug-using history, the remaining Irish women stated that they did not have ever used drugs nor had multiple sexual partners. In a similar vein, the African-born women rejected the idea that they too fitted the HIV stereotype as one who is sexually promiscuous, attributing their HIV status to the promiscuity of previous male partners. Campbell and colleagues (2007) claim that the interplay between social and psychological factors, including the link between HIV and sexual morality, is a stigma driver, certainly within many African contexts. It is likely that the African women's previous knowledge of HIV/AIDS, which includes the loss of relatives to AIDS, has a lasting legacy and affects their beliefs about its related stigma. This legacy shaped their collective fear or anticipation of stigma resulting in some of them continuing to conceal their HIV status. Furthermore, they expressed concern about the consequences of their diagnosis for their extended family in their home countries. They believed that if those in their home communities knew that they were HIV positive, their families could be subjected to stigma by virtue of this association.

There is evidence that the impact of biographical histories of HIV does affect the experiences of HIV positive migrant women (Doyal 2009, Ndirangu and Evans 2009, Foreman and Hawthorne 2007). This study suggests that previous knowledge of the stigmatising nature of HIV within certain African countries shapes the experiences of HIV positive migrant mothers, supporting Campbell and colleagues (2007) stigma model that emphasises its social components. It could be said that normalisation means different things in different contexts; the African participants' history of living in communities where HIV is still considered a feared fatal illness renders their perception of normalisation as less meaningful. While normalisation brings with it a conceptual shift of perceiving HIV as fatal to perceiving it as a chronic illness, their biographical history makes it difficult for them to accept this new discourse. As noted earlier women from Sub-Saharan Africa make up a significant percentage of new HIV diagnoses in Ireland. This study's insight into this specific aspect of culturally held beliefs, while acknowledging that Africa is a continent of many diverse cultures, is timely and warrants acknowledgement.

However, while some women worked hard to portray themselves in a positive light, some of the narratives suggested that nonetheless a number of women had a self-image reflective of the HIV stigmatised stereotype (Link and Phelan 2001). This study found that some mothers experience 'felt' stigma. These narratives build on and provide insight into the findings from an

Irish based stigma attitude survey that revealed that the perception that those with HIV are viewed negatively is higher among HIV positive individuals than in the general public (The National Stamp out Stigma Campaign 2007).

Some mothers in the study had other social issues to deal with apart from HIV; a number were single mothers, others were socially isolated and some were asylum seekers. Irish based asylum-seeking mothers face additional social challenges apart from HIV, including a prolonged immigration process and living in accommodation that is often not appropriate for families, which affects their wellbeing. Asylum-seekers, regardless of their health status, are often socially excluded and isolated (Foreman and Hawthorne 2007) and this accentuates their sense of stigma. The concept of 'mothering on the margins' seeks to recognise the experiences of mothers who are on the borders of society and considered socially excluded (Craig and O'Dell 2011, Phoenix 2011) and who may have to care for their families under difficult social circumstances. Additionally, their socio-economic situation, which includes adjusting to a new cultural environment, living with a minimal income and not being allowed to work, makes life extremely difficult for these women. They remain on the margins of Irish society irrespective of their HIV status (Sheehan 2013) and this is supported by previous research with migrant HIV positive women (Ndirangu and Evans 2009, Foreman and Hawthorne 2007). The findings of this research underscore the burden of HIV related stigma for HIV positive migrant women, while taking account of the other challenges they are dealing with.

Additionally, the concept of intersectionality (Campbell and Gibbs 2009) acknowledges the multiple dimensions of the gendered HIV experience and emphasises identifiers of HIV stigma overlap. This study's narratives support the notion of intersectionality for HIV positive mothers. Furthermore, within the study's sample there were women from both high and low HIV prevalence countries compared to other studies with HIV positive mothers (Walulu 2011, 2007, McDonald 2008) suggesting that HIV stigma persists even when access to HIV treatment is not an issue. Flowers (2010) asserts that due to the increasing acceptance of HIV normalisation, HIV stigma is increasingly considered a minor issue despite evidence to the contrary. My research demonstrate that stigma remains a key concern for mothers.

Having considered the three identifiers of HIV stigma, which are tolerating stigmatising behaviour from relatives and friends; dealing with HIV stereotyping; internalising a sense of being devalued, the section to follow considers issues of disclosure.

### 5.3.2 Disclosure

The decision to share one's diagnosis frequently occupies the thoughts of those living with HIV (Squire 2014) and participants' willingness to disclose, and the consequences of telling others featured centrally in their narratives. During the interviews, mothers spoke about deciding who might need to know, when to tell them and whether they could cope with the news. When sharing their diagnosis with those they were close to, participants were cognisant of the burden that disclosure can place on the recipient and on relationships, even though HIV is increasingly seen as a treatable condition.

Prior to disclosure, these mothers weigh up the possible consequences of others knowing, including the risk of attracting stigma and how others knowing could, in turn, affect their children. For these mothers, two kinds of disclosure were evident in the narratives: telling family and friends; and sharing their diagnosis with their children.

This study identified a number of factors that facilitate mothers telling family and friends, reasons for non-disclosure, and how being a migrant impacts on disclosure. Indeed those who told immediate family and friends found that it resulted in largely positive encouraging outcomes.

#### ***Factors that facilitate disclosure***

Analysis of this study's narratives reveals that four specific factors facilitate disclosure for mothers:

- Meeting other HIV positive individuals who have had positive disclosure experiences.
- A perception that telling others allows them to be more open about their condition and its impact which can result in increased support.
- Accessing support organisations.
- Support / encouragement from health and social care professionals.

#### ***Factors that inhibit disclosure***

The primary reason those who had told no-one apart from their medical team, peers and staff at the *HIV centre*, was their anticipated belief that disclosure would only result in negative consequences. Factors that inhibit disclosure include:

- An awareness of the negative disclosure experiences of other HIV positive people.
- A reluctance to burden others with the diagnosis.
- Fear of rejection by loved ones and unwanted third party disclosure.

Participants who shared their diagnosis with very few people seemed to embrace what Goffman (1986) described as a 'spoiled identity' and therefore were 'discreditable' from a stigma perspective. Non-disclosing mothers lack 'visibility' as known HIV positive women unless they tell others, indicating that the context of stigma did play a role in their management of information around their diagnosis and access to support. A lack of disclosure can relate to difficulties associated with acceptance of an HIV diagnosis, supporting Bravo and colleagues (2010) who theorise that telling others is part of the HIV acceptance and adjustment process. An interesting finding was that some women who were living with HIV for a number of years had told no-one or very few due to this fear of judgement by others. This suggests that Eustace and Ilagan's (2010) assertion that telling others becomes easier the longer an individual has been living with HIV may need amending, to account for mothers who remain non-disclosing many years after diagnosis.

#### ***How being a migrant mother affects disclosure decisions***

Particularly notable in the narratives of the African-origin mothers was that the decision to tell their family at home was complicated by two distinct factors. Firstly, they were living so far away from home and were unable to travel due to their migration status, and felt that disclosure is something that needs to be done face-to-face. Secondly, some had close family members who had died from AIDS, accordingly they were reluctant to burden their relatives with news of their own diagnosis. These two factors also made them cautious about telling others who were part of their African communities in Ireland. As noted earlier in this Chapter, relatives at home in Africa may be vulnerable to attracting potential stigma associated with having a known HIV positive member in the family, or might interpret a HIV diagnosis as life threatening. These narratives reveal how African participants position themselves in relation to the broader HIV agenda as this linking of disclosure with stigma is intricately bound to their experiences of HIV/AIDS in Sub-Saharan Africa. These reasons for non-disclosure have been reported previously with HIV positive African migrants (Ndiragwu and Evans 2008, Foreman and Hawthorne 2007, Flowers et al. 2006, Doyal and Anderson 2005, Anderson and Doyal 2004). This study confirms that African-origin migrant mothers' struggle with telling others is related to their previous experiences of HIV/AIDS. To summarise, participants who disclosed to



immediate family and friends found that it resulted in largely encouraging outcomes; moreover, these mothers felt that they could be somewhat open about their condition and its associated concerns due to this disclosure. However, some experienced judgement and rejection from family members on revealing their HIV status and this also led to a few incidents of unwanted third party disclosure. Those who had remained non-disclosing perceived that telling others would result in only negative consequences. These findings concur with previous research (Bravo et al. 2010, Eustace and Ilagan 2010). For MLH, HIV disclosure is a complex process influenced by their desire to shield others from the burden of HIV, their perception of HIV stigma and willingness to tell others, while examining the positive and negative consequences of sharing their diagnosis. However, this study reiterates that, for mothers the potential consequences that disclosure may have on their children is an additional factor to consider. Others agree that the maternal role influences mothers' disclosure decisions (Hunter and Longhurst 2013, Hunter 2009).

Very few of the mothers had shared their diagnosis with their adult and teenage children. The reasons that their older children were unaware of their diagnosis include a reluctance to burden them with the diagnosis and the desire to protect them from the perceived negative consequences of disclosure. These mothers of older children indicated their desire to protect their children from the burden of HIV and they felt there would not be any positive benefits to disclosing, despite the potential for receiving support from them.

In general, these mothers procrastinated about telling their older children; there never was a right time. A number of studies with mothers living with HIV have emphasised the challenges and complexities associated with mothers sharing their HIV status with their children (Walulu 2011, Hunter 2009, Hawk 2007). Murphy (2008) argues that older children, who do not know their mothers' status, usually suspect that something is wrong. Additionally, Bravo and colleagues (2010) propose that disclosure to older children can have encouraging outcomes bringing benefits to MLH (Delaney, Serovich and Lim 2008). In this study those who had shared their diagnosis with their older children overall found them to be supportive. The benefits of maternal disclosure to older children can outweigh the perceived negative consequences, particularly in countries like Ireland where HIV treatment is readily available. This is even within the increasing acceptance of HIV normalisation, emphasising the complexity of maternal disclosure for HIV positive mothers with older children.

Mothers with younger children expressed an intention to tell them in the future, some had attempted to gradually impart information to their children about their need to take tablets each day. Researchers have argued that avoiding telling children for as long as possible may be a coping strategy for MLH (Hunter 2009, Murphy 2008). Through these narratives, an understanding of the complexities of disclosure for mothers is evident and the fact that most participants spoke about it in their interviews indicates that it is an ongoing challenge for them. It appears that, for this study's participants, their belief that telling their children would be detrimental to them, irrespective of their age, contributes to their avoidance of disclosure for as long as possible. Having discussed disclosure as it pertains to HIV positive mothers the next part of this Chapter considers other significant psychosocial themes in this study including how the women managed being HIV positive, accessed support options, and their on-going concerns about protecting their children from HIV.

### **5.3.3 Mothers minimising HIV**

There was a sense amongst many participants that they consciously minimised the impact of HIV on their daily lives a finding that concurs with research reviewed in Chapter Two (Anderson et al. 2009, Stevens, and Hildebrandt 2006). However, this study highlights that mothers intentionally minimise HIV to focus on caring for their children. Within many of the narratives, being HIV positive did not appear to impinge largely on daily lives because most participants were physically well and compliant with medication. Even those who had HIV related complications did not elaborate about this in any detail. In this study, maintaining normalcy involves continuing with everyday mothering activities and dealing with their children's needs while keeping HIV in the background. Crossley's (2000) and Ezzy's (2000) earlier work with HIV positive gay men in the pre-HAART era identified normalising the experience of being HIV positive as a positive coping strategy. These studies were illness-orientated, whereas in the current study, illness was not the focus and mothers face different life challenges to gay men. Mothers living with HIV concentrate on caring for their children and minimising the impact of HIV when possible. It appears this is a way to manage and deal with the condition, demonstrating that HIV normalisation is possible in aspects of their lives.

### **5.3.4 The importance of peer support**

The mothers who had shared their diagnosis with family and friends described benefiting from the resultant support and practical help. In addition, they described a need to access support from outside the family and meet others in the same situation and this led them to access the HIV centre. Participants who had told no-one apart from their medical team also spoke about the importance of meeting peers, that is, others living with HIV. As noted earlier, the experience of being an Irish-based asylum seeker can be isolating and so the HIV centre provided a social space for the migrant women who did not have the same support options as had the Irish mothers. This study's narratives confirm that these women experience bonding social capital (Putman 1995), in this instance by meeting other HIV positive individuals at the HIV centre; attendance at the centre enhances their bonding social capital as meeting peers reduces isolation and allows for the development of enduring friendships. This is consistent with previous research on the support needs of HIV positive individuals (Bravo et al. 2010) and HIV positive women (Walsh et al. 2012, Foreman and Hawthorne 2007). Indeed, the role the HIV centre played in increasing bonding social capital of the participants is noteworthy, as it demonstrates the value of support, particularly peer support, for these mothers because of the exceptionality of being HIV positive.

### **5.3.5 Continuing to protect children**

An important concern for some mothers in this study was the on-going protection of their children from HIV and this remained even after the confirmation of their children's HIV negative status. In some accounts, mothers expressed anxiety about possible contagion within family settings; even though they were very aware of how HIV is transmitted, they worried about they could infect their children through normal mother-child interactions or minor blood spills. This finding matches those observed in previous studies (Walulu 2011, Sayles et al. 2007, Long 2009b, 2006). Ingram and Hutchinson's (2000, 1999) pre-HAART study proposed that MLH practice 'defensive mothering'; one aspect of this includes mothers attempting to reduce the possibility of their HIV negative children encountering infected blood in the home. Possible HIV contagion remained a concern for some participants regardless of the low likelihood of transmission within the intimate family context, suggesting that they too practiced 'defensive mothering' (Ibid). Importantly, as discussed in Chapter Two, effective antiretroviral treatment reduces infectiousness (Persson 2012) and these mothers concerns

about infecting their children is largely unfounded. The adoption of a narrative approach in this study revealed aspects of the maternal HIV experience that can remain unsaid, that is their heightened sense of perception of risk.

## **5.4 Conclusion**

This Chapter considered how mothers deal with the consequences of an HIV diagnosis. The possible ramifications of the diagnosis for their children or unborn babies was a key concern for these women. The maternal HIV diagnosis experience involves a two-stage process; mothers are initially concerned with establishing their child's HIV status and then subsequently deal with their own personal needs. It is apparent that HIV interferes with their lives as stigma remains a key issue for them, influencing how they deal with sharing their diagnosis with others. Disclosure is a complex process for mothers living with HIV and this study documents that revealing one's diagnosis to significant others( including children) is difficult. Significantly, these findings reveal that for the mothers in this study their frame of reference was their children and families and they strove to maintain normalcy in their everyday family lives. Davis and Squire (2010) argue that HIV normalisation has resulted in a lessening of consideration of the psychosocial impact of being HIV positive. However, this study's findings propose that HIV normalisation is context specific and it was noted that the personal biographies of women from Sub-Saharan Africa, where HIV is still considered a fatal condition, profoundly influenced their HIV experience.

These narratives endorse that an HIV diagnosis influences many aspects of mothering and being a mother shapes the experiences of HIV positive women.

## ***Chapter Six: Conclusion***

### **6.1 Introduction**

This Chapter reviews the study and summarises its contribution to knowledge and practice. It presents an overview of HIV mothering generated from the study, provides a summary of the main findings, discusses the use of a narrative methodology and presents recommendations for those who care for MLH and for further research in this area. This original study was concerned with an analysis of the narrative accounts of eleven mothers living with HIV in Ireland, exploring how these mothers construct meaning as HIV positive mothers. By telling their stories of mothering, participants were able to voice their feelings and reflect on their lives.

### **6.2 Thesis Summary**

The research question for this study was posed as “What are the experiences of mothers living with HIV in Ireland?” Adopting a narrative approach it set out to explore how HIV positive mothers negotiate and construct meaning in their lives. As indicated in the literature review, the predominant discourses of research on mothers with HIV have focused on the prevention of vertical transmission. By contrast, this study offers insights into the lived experiences of Irish based HIV positive mothers. The evidence from this study is that few mothers consider themselves as being defined by HIV, and focus on their maternal role and a strong sense of responsibility to their children. Their priority is meeting their children’s needs before they focus on themselves.

#### **6.2.1 Mothering in an HIV normalisation era**

HIV is frequently associated with sexual promiscuity and any association with this, for mothers, can potentially hinder their ability to relate to the norm of the ‘good mother’. Most of the study participants portrayed themselves positively in their narratives when they spoke about how normal their family life is, indicating that society’s expectations of mothers did influence them. This research documents the experiences of mothers living with HIV who face both

physical and social challenges due to their HIV status. Their largely positive portrayal of mothering while HIV positive suggest it is difficult for these women to express negative feelings or dissatisfaction about their experiences. The adoption of a women-centred approach in the data collection allows for their perspectives on their situation to be distinct and clear.

Researchers have argued that the unrealistic 'perfect' mother image persists despite the fact that the reality is very different for many mothers (Phoenix 2011, O'Reilly 2008, Miller 2007, 2005). This study explored experiences of HIV positive mothers across different points on the mothering trajectory including mothers of preschool, school aged, adolescent, and adult children. This research confirms that contemporary and cultural maternal discourses shape the participants' mothering experiences. Hunter and Longhurst's (2013) recent research with MLH in Canada suggests that they behave as 'selfless mothers' which means consistently putting their children's needs ahead of their own, even though their own health may warrant attention. This study shows that participants adopt this 'selflessness' from the moment of diagnosis whereby their primary concern becomes the establishment of their children's HIV status over and above their own personal needs.

It has been argued that feminist mothering theorists provide understanding into the varied mothering experiences, however Middleton (2006) contends that they need to broaden their scope of interest to include women who mother in challenging circumstances, and this study suggests that such circumstances should include living with illness. It is noteworthy that women who mother while dealing with other chronic physical illnesses, for example arthritis or cancer, face challenges; however they do not usually attract judgement from others due to their condition; they neither have to deal with the risk of VT nor with a fear of judgement by others that they brought this condition upon themselves. For HIV positive mothers this fear of potential judgement by others affects their HIV experience.

Some mothers appear to deliberately minimise the negative aspects of being HIV positive, for example lethargy or dealing with persistent side effects of medication. Significantly, the narratives revealed that most of the mothers were physically well and that HIV did not impact on their lives as they focused on family and future plans; it could be said that in a sense these women have embraced the contemporary medical construction of HIV as a treatable condition. By contrast, other narratives emphasised stigma and disclosure as being central to their HIV experience. For most, their HIV diagnosis was a salient life event and their transition from being HIV negative to HIV positive had wide-ranging consequences for their lives. This

confirms that HIV can be viewed as a double issue, strategically normalisable and sometimes minimisable, but always addressed from their perspective as mothers.

### **6.2.2 Summary of Findings**

In these narratives, the continued nature of the psychosocial impact of an HIV diagnosis for mothers was evident. Arising from this study the key insights to the understanding of the maternal HIV experience may be summarised as follows:

- The research provides understanding as to how mothers at different points on the mothering trajectory (including mothers-to-be) deal with an HIV positive result.
- Many participants were unprepared for an HIV positive result due to a misconception of risk on their part.
- The study has shown that a shared significant experience upon diagnosis for mothers was to prioritise viral testing of their children. This 'child-centeredness' dominated their response to an HIV positive result.
- One of the more significant findings to emerge is that some pregnant women may have an exaggerated sense of the potential for vertical transmission occurring, despite being assured that it is preventable and that the likelihood is low. This concern was evident in both newly diagnosed women and those that had been living with HIV for some time.
- Stigma remains a concern for mothers in the HIV normalisation era and, in particular, there was evidence of 'felt' stigma that affects the HIV experience.
- The study has shown that there is a lasting impact of the HIV legacy for African-origin mothers indicating that HIV normalisation means different things in different contexts and that it still an aspiration for many living with HIV.
- These findings enhance our understanding of how mothers living with HIV manage disclosure and how being a mother impacts on who they tell.
- For most of the study participants, there was never a right time to share their diagnosis with their children.
- The study found that most of the mothers manage HIV by minimising it in everyday life while focusing on caring for their families. Participants spoke about envisaging a normal future watching their children growing up, which reflects the increased

acceptance that those with HIV will not die prematurely and that HIV normalisation can be a reality.

- Peer support is important to MLH and there was evidence that their attendance at the *HIV centre* enhanced bonding social capital.

Certainly, the ongoing stigmatisation and marginalisation of those living with HIV present unique challenges to mothers compared to other chronic illnesses (Bernays 2011, Flowers 2010). This study re-iterates that the HIV experience is distinctive for mothers compared to HIV positive women who do not have children. Most of this study's participants have only been aware of their seropositivity in the era of HAART, which influences their experiences and stories. However, some were affected by previous experiences of HIV in Sub-Saharan Africa. Being HIV positive, did affect their mothering role despite their assertions that they were normal mothers.

### **6.3 Adopting a narrative approach**

Employing a narrative approach provides insight into the dynamics of being an HIV positive mother in the HIV normalisation era. This study employed an experience-centred narrative approach (Squire 2008a, 2008b) supported by Murray's narrative framework (Murray 2008, 2000). Most narratives were structured chronologically, starting with the HIV diagnosis and continuing with discussions of life as a mother with HIV, including their experiences of support, stigma, disclosure and daily life.

Indeed the process of telling their stories of life as a mother living with HIV involved organising the significant events in their lives since diagnosis and recounting their stories during the interview. This methodology suits the exploration of mothering as it promotes the use of reflection to make meaning in experiences (Frost 2011). For this study's participants, the storytelling process gave them an opportunity to make meaning of their experiences. McLeod (2011) proposes the richness of narrative analysis is respecting how stories are told, as they can be a mixture of the past, present and an imagined future.

While the findings from this study add to the understanding of the maternal HIV experience, it draws its conclusions from a small number of participants, reflecting their individual experiences and the author's interpretation of their accounts. The study documents participants' stories of mothering while HIV positive, which were co-constructed during the



interviews, and my interpretation of these accounts. Additionally, the context of the interviews is significant for the collected narratives. The researcher, as a nurse, lecturer, and mother, created new contexts when interpreting their stories. Additionally, Murray's narrative analysis framework (2009, 2000) facilitated considering narrative elements such as tone, imagery and metaphors within the narratives as they often supplement the overall understanding within a story and how the individual makes sense of an experience. It also allowed for exploration of how the narratives relate to cultural/societal contexts, which has particular significance for those with HIV, given the particularity of their challenges.

Many of this study's findings support and extend research examined in the literature review, accentuating the gender dimension of being HIV positive. Unlike research with HIV positive women examined in the literature review, in which mothering experiences emerged during data collection, in this study's narrative approach attention was focused on mothering from the outset.

The study presented a wide-ranging overview of HIV positive mothering narratives as it included women who were mothers prior to diagnosis, who were diagnosed when pregnant (including first time mothers-to be), and those who became mothers after their HIV diagnosis. Additionally, it was conducted in a low HIV prevalence country with participants from African countries, Europe and Ireland, and so presents a range of mothering experiences. All participants had access to HAART, although many of the African-origin women had personal experiences of the fatal consequences HIV at home. The inclusion of African migrant mothers in this study allowed for documentation of their experiences as such documentation has been minimal in the literature. Documenting their perspective is also of importance as women of African origin represent a significant percentage of newly diagnosed mothers in Ireland and the UK.

The analysis of the narratives drew on a combination of theoretical perspectives including feminist mothering theory, HIV stigma frameworks, social capital theory and the medicalisation of HIV. As HIV is a complicated condition with physical, psychological and social consequences for those living with it, the analysis of the interview data necessitated the inclusion of these selected theoretical perspectives to support data interpretation. Analysis of the rich data from these narratives, using multiple theoretical viewpoints, adds to the literature on contemporary HIV experiences.

## 6.4 Reflexivity

As this thesis draws to a close, I want to reflect on this research process, as being self-aware is paramount in narrative research. During this study, self-awareness had a higher significance as I too was a participant in the research process, co-constructing the narratives with the women and, in turn, interpreting meanings within their stories. My analysis of the narratives reflects my own story as I created new contexts when interpreting the mothers' stories. This study was always more than an academic exercise, it was a personal endeavour for me, and it has been a privilege to meet these women, document and interpret their stories, and compile and present them in my thesis. I have learned a lot through the process and, most of all, I have learnt how HIV positive mothers can overcome a life-changing diagnosis by remaining child-centred throughout.

## 6.5 Recommendations for further research

This research broadens our understanding of how being HIV positive impacts on the mothering role and more research on mothers living with HIV is needed to further explore their lives and experiences taking into consideration the exceptionality of HIV. Further research could include the following:

- It is apparent that HIV positive migrant mothers face additional challenges compared to the Irish and European women. Further research with HIV positive migrant mothers from high prevalence HIV countries to examine their experiences of mothering would be useful, as they are the largest group of newly diagnosed women in Ireland in recent years. HIV is one of multiple issues they may be dealing with and it was apparent that their biographical experiences of HIV as a fatal, feared disease affected how they dealt with their own diagnosis.
- Maternal disclosure appears to be particularly complex. It would be interesting to explore this in more detail to provide insight on why it is so difficult for mothers to share their diagnosis with their children, even when they are old enough to deal with the news, and when the health outcomes for those who are HIV have improved.
- Some participants had lived with HIV for many years and their stories spanned the changing outcomes for those who are HIV positive due to the treatment advances. Adopting a longitudinal approach to the experiences of mothers living with HIV, to

follow and document their lives over the next couple of decades, would be valuable, as longevity becomes the norm for those who are living with HIV.

- Two of the women were diagnosed in middle age and so had additional concerns to the younger women. There is an increased focus on how those who are HIV positive are ageing (Owen and Catalan 2012) and there is indeed scope for exploring how HIV positive mothers deal with ageing.

## **6.6 Recommendations for healthcare providers**

The concerns of HIV positive mothers post-diagnosis have received little research attention. This study will assist clinicians and healthcare staff to appreciate the experiences of mothers living with HIV as they face different challenges to other individuals living with HIV. For most of the participants their HIV positive result was unexpected even though many of them were actually at risk of HIV infection, suggesting they were unprepared for a HIV positive result. This lack of preparation reiterates the importance of identifying those at risk prior to the blood test to ensure that they are better prepared for the possibility of an HIV positive result. For mothers, as the subsequent response to the news is to focus on the ramifications of the diagnosis for their children or unborn babies, this means that their own personal needs are secondary and may be neglected

Importantly, healthcare professionals rarely acknowledge the centrality of being a mother for those they care for (Vallido et al. 2010). This study provides insight into the subjective experiences of HIV positive mothers and it is apparent that they invest heavily in their mothering role. Health professionals must recognise the importance of this role and adopt a mother- centred care approach, particularly after an antenatal diagnosis, during pregnancy and following the birth of their HIV negative children. For MLH, challenges persist even if their child is HIV negative.

Arising from this study's findings it appears that some pregnant HIV positive women may overestimate the risk of VT suggesting that more support and information about the real risk is warranted. Their decision around HIV treatment options are made with the primary concern being for their children rather than themselves and this can, in turn, affect their health and wellbeing. Health professionals need to acknowledge mothers' dual identity and how being HIV affects their mothering role and vice versa.

## **6.7 Close**

This important research provides in-depth understanding into the mothering experiences of HIV positive women living in Ireland. HIV remains a difficult condition to live with even in this HIV normalisation era. By attending to the participants' stories, the meaning of being a HIV positive mother is apparent. Consequently, this study highlights the importance of understanding the lives of mothers living with HIV in Ireland to compliment the dominant biomedical HIV discourses. This study's narratives provide insight into the other side of the story of being a HIV positive mother other than that of the medical perspective.

As a final word, there can be no doubt that an HIV diagnosis influences many aspects of mothering and being a mother shapes the experiences of HIV positive women.

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## ***Appendices***

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## ***Appendix 1 Participant Information Sheet***

**Study Title: An exploration into the experiences of HIV positive mothers living in Ireland.**

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully.

Part 1 tells you the purpose of this study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study.

### **Part 1**

What is the purpose of the study?

The purpose of this study is to explore the experiences of HIV positive mothers. This study is a student research project.

Why have I been invited?

I would like to learn about your life as an HIV positive mother who attends *this HIV centre*. I hope to interview 15 mothers.

Do I have to take part?

No. It is up to you to decide whether to take part. If you do, I will describe the study and go through this information sheet, which I will then give to you. I will then ask you to consent to take part. You are free to withdraw at any time, without giving a reason or a decision not to take part.

What will happen to me if I take part?

You will be required to partake in one interview with the researcher.

What are the possible disadvantages and risks of taking part?

It is not the intention of the research to cause any distress to you during the course of the interview. If however, for any reason you become upset, you can access the support services within *the HIV centre*.

What are the possible benefits of taking part?

The information received will help to generate knowledge on the lives and experiences of HIV positive mothers living in Ireland. This interview will allow your story to be heard and in turn may inform those who care for you about your life as an HIV positive mother.

Will my taking part in this study be kept confidential?

Yes. All information about your participation in this study will be coded to protect your identity. The details are included in Part 2 of this form.

Contact Details, Researcher: Denise Proudfoot Contact Number: 0871200247

If the research study has interested you and you are considering participation, please read the additional information in Part two before making any decision.

## Part 2

What will happen if I do not want to carry on with the study?

You can withdraw from the study at any time.

What if there is a problem?



If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your question (phone number). If you remain unhappy and wish to complain formally, you can do this through the University of Bath Complaints Procedure. If you become distressed or upset during the interview it can be stopped and you can access the support staff with in *the HIV centre* or your social worker at your treatment centre.

Will my taking part in this study be kept confidential?

With your permission, I will use an audio tape recorder to record our conversation.

All the data collected will be stored securely. If you join the study, the data collected may be looked at by the University of Bath to check that the study is being carried out correctly. All possible steps will be taken to treat responses as confidential. Any information about you, which leaves the researcher, will have your name and address removed so that you cannot be recognised from it. You should also know your privacy will be respected however confidentiality cannot be guaranteed if disclosure is made about the safety of a child during the interview.

Who is organising and funding the research?

This research is part of a Professional Doctorate Programme at the University of Bath, United Kingdom and the researcher's employer is funding the study.

Who has reviewed the study?

All research conducted through the University of Bath is reviewed by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. The management team at this centre have also given consent for the study to take place.

Thank you for considering taking part and taking the time to read this information sheet.

Denise

## Appendix 2 Consent Form



Study Title: An exploration into the experiences of HIV positive mothers.

### Consent Form for Participants

		Yes	No	N/A
1	I have read the information sheet. I understand what the research is about.	<input type="checkbox"/>	<input type="checkbox"/>	
	I have been given the chance to ask any questions I may have.	<input type="checkbox"/>	<input type="checkbox"/>	
	If I have asked questions, I am happy with the answers I have received.	<input type="checkbox"/>	<input type="checkbox"/>	
	I understand it is my decision whether or not to participate. If I agree now, I can change my mind and do not have to give a reason.	<input type="checkbox"/>	<input type="checkbox"/>	
	I understand that withdrawal will not result in any negative impact or penalty.	<input type="checkbox"/>	<input type="checkbox"/>	
	I understand that the information I provide will be treated as confidential.	<input type="checkbox"/>	<input type="checkbox"/>	
	I understand that only members of the research team will have access to data and that all data will be securely stored.	<input type="checkbox"/>	<input type="checkbox"/>	

I agree that my interview will be audio-recorded. ☐ ☐

I understand that I can request a copy of the interview transcript ☐ ☐  
from the researcher and it will be available to read *@the HIV centre*

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Name of participant

Date

Signature

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Name of researcher

Date

Signature

### ***Appendix 3 Interview Guide***

Introduction: Thank you for taking the time to allow me to interview you about your experiences. I have prepared some questions I would like to ask you and please speak freely about your life.

- Can you tell me about your experiences/your story of being a mother living with HIV?  
*What has helped /hindered your mothering experiences?*
- What have been some of the most positive aspects of being a mother for you?
- Can you tell me of any experiences of discrimination/unfairness you may have had due to your status? How has this impacted on your mothering/children/ family life? Can you remember a particular time when...?
- How do you feel about telling others about your HIV status? Can you share some experiences you have had?
- If you have decided not to tell others (friends, family) about your HIV status, why haven't you? Do you intend to disclose your status in the future?
- Can you tell me about your own support networks? (who helps you, what support agencies to do access). What about internet, health professionals, church?
- Is there anything else you would like to tell me?

Prompts: Tell me what happened? Can you remember a particular time when? Are there any other times when you felt like this? How did you deal with that? What do you mean by? Would you explain this in more detail? Can you describe...

#### ***Appendix 4 Demographic information***

Following today's interview there are some questions which I would like you to complete. You may omit any questions you do not want to answer. Please complete sections that apply to you.

Age range please tick

20 to 30 ☐

31 to 40 ☐

41 to 50 ☐

51 to 60 ☐

Decline ☐

Estimated time when you became positive

.....

Date of HIV

diagnosis.....

.....

Are you currently taking anti-retroviral therapy ?

Occupation

If you are currently not in paid work, what kinds of work have you  
done?

How do you spend your

time?.....

.....

Thank you Denise

REF:

Date of Interview :

## ***Appendix 5 Research Proposal to HIV centre***

20/12/2010

To *HIV centre*:

My name is Denise Proudfoot and I am a lecturer in nursing @Dublin City University and a doctorate student at Bath University, UK. I would like to ask the members of *HIV centre* help, to conduct a study into the experiences of HIV positive mothers. Through your participation, it is hoped to document the experiences of mothers living with HIV in Ireland. The proposed qualitative narrative study will explore the challenges faced by mothers who are HIV positive. It will explore how being HIV positive impacts on their experiences as mothers and on their daily lives. The members of the *HIV centre* and the organisation will be acknowledged in any publications or presentations based on this research. I will provide the *HIV centre* with a summary report of the research findings for use by the organisation including its publications. I will also submit a copy of my published thesis to *the HIV centre* on completion.

I want to interview mothers who are members of *this HIV centre* have enclosed a Participant Information Sheet which gives more details about the study. This study has full ethical approval from Bath University, UK and I will adhere to guidelines on conducting research in an ethical manner.

I would like to thank you for taking the time to consider this research proposal. If you need any further information, or would like to discuss any aspect of the research further, please do not hesitate to contact me. I have provided further details of the research process on the following page.

Yours Sincerely,

Denise Proudfoot

## Research Procedure:

Mothers who are members of *the HIV centre* will be approached by the Women's Space Coordinator to see if there are interested in being interviewed. They will be given a copy of the study information sheet (appendix 1) which outlines the study. If after reading the information sheet, they will give permission for the researcher to contact them by phone to arrange an appointment for the interview. It will be made explicit that participation in this study is voluntary and participants may withdraw at any stage of the research process. I hope to conduct the interviews (which will be audio taped) at *the HIV centre*. The interviews will be approximately an hour long. Prior to the interview each participant will complete a consent form (appendix 2). I shall book an interview room in advance through the Membership Officer (MO) and inform the MO when each interview is being taken place.

**Timeline:** I hope to start the data collection (interviews) in January 2011 and it will run until March 2011 approximately.

### **Number of participants**

I would like to interview 15 women who have child/children over 6 months of age. Participants need to be over 18 and have their HIV diagnosis for at least 6 months. It is preferable that all potential participants speak English.



## ***Appendix 6 Interview Summaries***

**Note: Pseudonyms were allocated to each research participant**

**KATE** is an Irish born former nurse who has lived with HIV since 1988. She is married, her husband is HIV negative, and they have two boys aged 9 and 4 years. When she was initially diagnosed, she did not think she would have children and really enjoys being a mother.

**Beginning** Kate began the interview by describing what led to her diagnosis, her initial reaction to the unexpected news and how it affected her. As someone diagnosed in the late 1980s she faced many health challenges and did not expect to live very long. She described experiences of telling others including her family. She presented a coherent overview of the experience of being HIV positive in the late 1980's and early 1990s and spoke about not being able to identify with other HIV positive women when she eventually accessed HIV support agencies in London.

**Middle** Her story focused on her life as a mother and the challenges of ageing while HIV positive. Kate also described how challenging it is to have an HIV negative partner and how she has dealt with disclosure to others.

**End** The challenges of ageing while HIV positive featured as the interview ended. Kate currently takes a variety of medications to deal with her other health conditions. She ended the interview by speaking about being more comfortable as an HIV positive woman after living with the disease for so long.

**MAUD** is a single mother from the Cameroon with a three-year-old daughter in her mid-twenties. She was in Ireland six months when we met.

**Beginning** Maud described that she found out that she was HIV positive as part of health screening when she came to Ireland to see asylum. On diagnosis, her thoughts immediately turned to her young child and she was very relieved that her daughter was confirmed HIV negative.

**Middle** The interview took an unexpected turn when I enquired about her daughters' father as she disclosed her father (now deceased) had raped her and she had become pregnant by him. This incest had contributed to her decision to leave the Cameroon and seek asylum in Ireland. I was not aware of her circumstances prior to interview so asked her if she was getting support for it and she indicated that she was and did not refer to it again.

**End** The latter part of the interview was future focused as Maud spoke about her and her daughters' future and that she was grateful to be in Ireland.

**EVELYN** is a middle-aged African woman who has been HIV positive since 2005.

**Beginning** Evelyn started the interview expressing her gratitude at been invited to tell her story. As a Zimbabwean woman in her fifties who had lived in Ireland for the last 10 years, she is a retired nurse but also worked as a teacher previously. Evelyn told me about her late husband who had been unfaithful and had fathered 21 children and blamed him for infecting her with HIV.

**Middle** Evelyn described her life before she came to Ireland and that she had trained as a nurse in the UK. Her two adult sons are aware of her status and they did live in Ireland and now are back in Africa. She has had physical health problems recently and did express some concern about how long she would live. She said that she did not feel she looked like someone who was HIV positive, as she was overweight. She talked about knowing others that were positive by their eyes. She claimed individuals with HIV had a yellow tinge in their eyes

**End** The latter part of the interview focused on her life in Ireland and the isolation she feels at times because of her health and lack of money she does not get to visit the HIV centre as much as she would like to. Her two adult sons and five grandchildren are all living in Africa and she would like to see them more. Additionally she felt she would not live long due to her HIV status.

**JOANNE** is an Irish single mother of a 15-year-old boy who has lived with HIV since 1997.

**Beginning** She started the interview by telling me that she is not any different to other mothers. She said that compared to her sisters (she comes from a large family) she copes well as a mother. She became HIV positive following a relationship with a known HIV positive man who she met while volunteering in an HIV centre. Joanne said she knew she was HIV positive when she discovered she was pregnant with her son. Her pregnancy was difficult. Her mother was diagnosed with cancer during it and subsequently died when her son was only 6 weeks old.

**Middle** Joanne spoke about her life since her diagnosis and her support networks. She recounted how she has managed and that she gets a lot of support from her family and friends but they too have had many problems. Joanne also said that she has deliberately avoided having a boyfriend until her son was older and she is contemplating a relationship now. She has worked in

various jobs and has never disclosed her status to any employer, as she did not feel it was relevant. She spoke about how her diagnosis affected others, in particular a close friend who she recently told and how he dealt with it

**End** She got a lot of support from her mother while adjusting to her diagnosis so her death was a huge loss to Joanne. She has experienced a lot of loss in her life as two of her siblings have also died. She described her relationship with her teenage son as close and spoke about him a lot during the interview. She has tried to protect him from knowing her diagnosis and does not know when it will be the right time to tell him about her HIV status, as he is gay. She feels this complicates things.

**BARBARA** is an Irish separated mother of three adult children

**Beginning** Barbara's diagnosis with HIV three years ago was a big shock as she is unsure whether she was infected by her previous or current partner, as both are HIV positive. Barbara described her knowledge level of HIV as minimal before she was diagnosed and has found attending the HIV centre very informative and reassuring.

**Middle** She spoke a lot about her adult children her daughter in particular who is a single mother of two small children. Barbara described their relationship as challenging. Disclosure of her HIV status was an issue for Barbara as people including her ex-husband knew about her diagnosis and she would have preferred if they did not. One of her sons has spent time in prison and she does not see much of him.

**End** The interview ended with Barbara telling me about her grandchildren and how she enjoys spending time with them. She is also was doing a FETAC course in catering and hopes to secure work in the future.

**GRACE** is a mother of three from the Cameroon who has been in Ireland since 2008.

**Beginning** As the interview began, Grace told me about losing her husband to AIDS in 2005 and that she was diagnosed when pregnant. Her youngest son (8 years) is HIV positive and he is in Ireland with her. Her older children are in Africa. As an asylum-seeker, she is living in designated accommodation and is not happy living there.

**Middle** As the interview progresses Grace became more upset and began to cry as she told me she was worried about her son and trying to get him to eat as he did not like the food in their accommodation and she could not afford to but African food which he preferred. She then admitted to being depressed

and admitted to thinking about suicide. At this point, I suggested we take a break and with her consent, I spoke to the women's support worker as I felt she needed to have a mental assessment as a priority.

**End** The interview ended at this point, as it was not appropriate to continue when she was so upset so I handed her over to the support worker to contact her GP.

**SABINE** was diagnosed in 2009 and is originally from Eastern Europe.

**Beginning** She told me that she is now a single mother of a 13-month-old daughter. Her ex-partner and father of her daughter were diagnosed after Sabine. She came to Ireland four years ago spoke about 'bettering herself' so that she and her daughter will have a future.

**Middle** During the interview she described that her brother also lives in Ireland knows about her status as her ex-partner told him against her will. Her family back home are unaware and she has no plans to tell them as she feels they would find it difficult to accept it. She said that people in her home country would be very judgmental of someone who is HIV positive.

**End** The interview with Sabine telling that she sees herself as a normal mother and her hopes for the future. She volunteers at the HIV centre and enjoys coming there.

**SHARON** is an Irish mother of two daughters who are 24 and 6 years old.

**Beginning** Sharon has lived with HIV for the last 11 years. Sharon's partner and father of her youngest daughter is HIV positive and an ex-IVDU. Very early in the interview, Sharon spoke about her difficulties with having a baby as an HIV positive woman, and spoke at length about the difficulty she has had in accepting that her younger daughter was HIV negative

**Middle** She has only recently sought support around HIV and appeared to be slowly coming to terms with the diagnosis. She has told none of her family or friends about her diagnosis so her only source of support has been her partner. She frequently referred to the possibility of discrimination due to her disclosing her HIV status. Sharon said in her opinion that those who are HIV positive are still subject to a lot of stigma. Sharon mentioned that she was surprised how open some women in the HIV centre were about their diagnosis.

**End** As the interview drew to a close Sharon spoke about her dilemma about sharing her diagnosis with her older daughter at some stage but still has not done it.

**ELIZABETH** is an asylum-seeker from South Africa who has two daughters.

**Beginning** The interview began with her diagnosis story as seven years previously Elisabeth was diagnosed when eight months pregnant as part of health screening for asylum-seekers. This South African mother of two primary school-going daughters is now settled in Ireland. Her ex-husband is in Africa and she is in new relationship with an Irish man (HIV positive), the father of her second daughter

**Middle** Elisabeth told me about a hospital admission when she was treated for TB for six months. She spoke about how hard it was to be away from her daughters (one was a baby at the time) when in hospital.

**End** She is planning to study to be a nurse and has completed a foundation-nursing course. She currently lives in designated asylum-seekers' accommodation with her children. Throughout the interview, she presented a very positive attitude towards living with HIV.

**ROSE** is a South African mother of three children who had been living with HIV since 1999.

**Beginning** Rose spoke about her life in Ireland as an asylum-seeker. She was originally diagnosed in South Africa prior to travelling from her home to Johannesburg to look for work. She left her son with her mother so that she could look for work. She appeared to suppress her initial diagnosis and was diagnosed again in Ireland in 2003 as part of antenatal screening when she was pregnant with her daughter.

**Middle** She admitted denying her initial diagnosis as she was too busy surviving and trying to get a job and said no one talked about it. Rose also said she was lucky to be here getting treatment and that if she had stayed in South Africa she would probably be dead.

**End** The interview ended as she told me that she lives with all of her children (her adult son joined her and completed his schooling in Ireland) on the outskirts of the city. She hopes to get work as a teaching assistant as she completed the training a few years ago.

**CIARA** is an Irish mother of one who has been HIV positive since 2007.

**Beginning** Ciara is an ex-intravenous drug user and has an eight-year-old daughter. She used drugs for over 12 years and on diagnosis, her life has turned around. She told me she had tried to detox from opiates a couple of times before but was only successful since she learnt of her HIV diagnosis.

**Middle** In the middle part of the interview, Ciara shared that she has become a born-again Christian and now manages a recovery home for other women who are trying to detox. She lives there with her daughter and is very busy with this job. Her family are aware of her HIV diagnosis and are supportive of her.

**End** Her interview ended with her telling me that she is currently engaged and her fiancé is also a Christian. They hope to have more children when they get married. She finds that helping others keeps her busy and does not allow her much time to dwell on her HIV status.

## ***Appendix 7 Interview Excerpt***

Excerpt from Sharon's interview when she discusses stigma and why she has not disclosed to her adult daughter.

D        Increasingly HIV is seen more as a chronic illness rather than a terminal illness yes but there's a difference,

S        Ya, I only found that out a couple of years ago, but like there is a terrible and I know I always say it, a stigma about it people don't know anything about it. I know about it I've always known about it but people just, they think, shake hands and they're going to get it or if you talking to them you know **yes** it's horrible like, society is horrible **yes**, it's cruel as well, that's why I don't tell anyone, I couldn't **yes** ah no way

D have you ever thought about telling your older daughter, do you think it's something you should do at some stage?

S This is where I actually want to do, because she is 24 this year **yes** and I do say to me self if anything happens to me like I don't know

D and is she close to your daughter?

S ah yes the two of them have a great bond, cause I'm always saying if anything happens to me you look after her, don't let anybody take her, you know like **yes** the little one loves her, like that's where I have to aim,

D        do you think she might even suspect something?

M        no, I hide everything, I just, everything was just hidden away with her, even when I found out I had it I was giving her certain towels to use that's how stupid I was like, I was terrible like, it was just me, just crazy **yes**, just,

**D** it sounds like a very long traumatic time for you and you know I just,

**S** Just, everything, medication was hidden from her, and when I'd go to the hospital she would be in school, I'd say walk up to one of me friends and I'll meet you there, because most of the time you can be hours in hospitals **yes** and she'd say where were you, and I'd say I just had to go for a few tests, and she'd say well what's wrong with you and I'd say nothing, there, don't be asking questions.

**D** So she doesn't live with you?

**S** No she moved out last year, she lives with her boyfriend now. I know I will have to tell her, that's what I am trying to aim for is to tell her **yes** sit down and have a talk with her.

**D** And not, I suppose what are your fears what are you afraid of when you do tell her, what's stopping you?

**M** I'll tell you, she'll probably blame me partner on it yes she knows like he's an ex drug addict, and he was very young, cause she'd often hear his family talk about it **yes** cause I'd a never told her, but she used to say to me like, and I'd say that was years ago when he was young, he's changed his life around, but I know she'd turn on him straight away cause she's that type of person.

**D** And are they close?

**S** She gets on great with him, she loves him, and he's like a father figure to her **yes** I suppose there's an awful lot there. I don't want to hurt her.

**D** Do you ever think she, she could help you, and she could support you through it

**S** I'd say to me self then I'd have an awful lot of pressure on her life she has to have her own life **yes** I don't want to be putting pressure on her neither.



## Appendix 8 Coding tables

Open Codes		
Codes	Sources Coded	Units of Meaning Coded
<i>being HIV positive</i>	<b>11</b>	<b>55</b>
<i>my children</i>	<b>10</b>	<b>58</b>
<i>coping with life with HIV</i>	<b>10</b>	<b>70</b>
<i>OHH</i>	<b>10</b>	<b>61</b>
<i>partner</i>	<b>10</b>	<b>41</b>
<i>my future</i>	<b>9</b>	<b>18</b>
<i>being diagnosed</i>	<b>9</b>	<b>34</b>
<i>telling or not telling others</i>	<b>9</b>	<b>32</b>
<i>telling family about HIV</i>	<b>9</b>	<b>31</b>
<i>telling my children</i>	<b>8</b>	<b>25</b>
<i>support from others</i>	<b>8</b>	<b>19</b>
<i>coping with HIV</i>	<b>8</b>	<b>17</b>
<i>knowing others who are HIV positive</i>	<b>7</b>	<b>17</b>
<i>HIV mothering</i>	<b>7</b>	<b>22</b>
<i>protecting my children</i>	<b>7</b>	<b>30</b>
<i>disclosure</i>	<b>7</b>	<b>25</b>
<i>discrimination</i>	<b>7</b>	<b>12</b>
<i>work</i>	<b>7</b>	<b>25</b>
<i>HIV treatment</i>	<b>6</b>	<b>12</b>
<i>family relationships</i>	<b>6</b>	<b>13</b>
<i>diagnosis stories</i>	<b>5</b>	<b>10</b>
<i>adjusting to HIV</i>	<b>5</b>	<b>20</b>
<i>pregnant and HIV positive</i>	<b>5</b>	<b>17</b>
<i>relationships with men</i>	<b>5</b>	<b>10</b>
<i>when you came to Ireland</i>	<b>5</b>	<b>11</b>
<i>infecting others</i>	<b>4</b>	<b>5</b>
<i>first diagnosed</i>	<b>4</b>	<b>7</b>

<i>where I live</i>	<b>4</b>	<b>7</b>
<i>asylum seeker</i>	<b>4</b>	<b>8</b>
<i>having a negative child</i>	<b>4</b>	<b>8</b>
<i>God</i>	<b>4</b>	<b>4</b>
<i>belonging others are the same as me</i>	<b>4</b>	<b>5</b>
<i>good experiences of being a mother</i>	<b>4</b>	<b>5</b>
<i>where I am from</i>	<b>4</b>	<b>4</b>
<i>normalising HIV</i>	<b>4</b>	<b>4</b>
<i>shock of diagnosis</i>	<b>3</b>	<b>3</b>
<i>leaving my children</i>	<b>3</b>	<b>5</b>
<i>money</i>	<b>3</b>	<b>3</b>
<i>protecting my unborn child</i>	<b>3</b>	<b>4</b>
<i>breast feeding</i>	<b>3</b>	<b>4</b>
<i>HIV illness</i>	<b>3</b>	<b>8</b>
<i>protecting others get a HIV test</i>	<b>3</b>	<b>3</b>
<i>HIV negative children</i>	<b>3</b>	<b>5</b>
<i>friends in the same boat</i>	<b>3</b>	<b>4</b>
<i>disbelief I was positive</i>	<b>3</b>	<b>3</b>
<i>being single parent</i>	<b>3</b>	<b>11</b>
<i>counselling</i>	<b>3</b>	<b>8</b>
<i>stigma</i>	<b>3</b>	<b>10</b>
<i>spiritual support help</i>	<b>3</b>	<b>3</b>
<i>death of family members</i>	<b>3</b>	<b>6</b>
<i>being young</i>	<b>2</b>	<b>2</b>
<i>over time</i>	<b>2</b>	<b>2</b>
<i>support from social worker</i>	<b>2</b>	<b>2</b>
<i>having more children when positive</i>	<b>2</b>	<b>6</b>
<i>career plans</i>	<b>2</b>	<b>7</b>
<i>being strong for my children</i>	<b>2</b>	<b>2</b>
<i>living in a foreign country away from friends</i>	<b>2</b>	<b>5</b>
<i>possibility of infecting my baby</i>	<b>2</b>	<b>2</b>
<i>people in Africa</i>	<b>2</b>	<b>2</b>
<i>physical illness</i>	<b>2</b>	<b>3</b>

<i>loss of family members to HIV</i>	<i>2</i>	<i>2</i>
<i>looking HIV positive</i>	<i>2</i>	<i>2</i>
<i>holidays</i>	<i>2</i>	<i>5</i>
<i>looking after myself</i>	<i>2</i>	<i>2</i>
<i>death of her husband</i>	<i>2</i>	<i>5</i>
<i>lack of cooking facilities</i>	<i>2</i>	<i>3</i>
<i>denial</i>	<i>2</i>	<i>8</i>
<i>safe sex</i>	<i>2</i>	<i>4</i>
<i>my relationship with my grandchildren</i>	<i>2</i>	<i>5</i>
<i>what lead me to become a mother</i>	<i>1</i>	<i>1</i>
<i>giving blood</i>	<i>1</i>	<i>1</i>
<i>feeling tainted</i>	<i>1</i>	<i>2</i>
<i>not much was known back then</i>	<i>1</i>	<i>1</i>
<i>a huge emphasis was on protection of others</i>	<i>1</i>	<i>1</i>
<i>bereavement</i>	<i>1</i>	<i>1</i>
<i>possibility of being a mother</i>	<i>1</i>	<i>1</i>
<i>my childhood</i>	<i>1</i>	<i>2</i>
<i>blood donor</i>	<i>1</i>	<i>2</i>
<i>the first clinic visit</i>	<i>1</i>	<i>4</i>
<i>social life while working and positive</i>	<i>1</i>	<i>1</i>
<i>drinking helped me cope</i>	<i>1</i>	<i>1</i>
<i>how unattractive I was</i>	<i>1</i>	<i>3</i>
<i>keep away from me</i>	<i>1</i>	<i>2</i>
<i>making the first move to contact the nice doctor</i>	<i>1</i>	<i>2</i>
<i>government</i>	<i>1</i>	<i>1</i>
<i>how long have you been in Ireland</i>	<i>1</i>	<i>1</i>
<i>previous experience of HIV in Africa</i>	<i>1</i>	<i>2</i>
<i>telling partner about HIV</i>	<i>1</i>	<i>1</i>
<i>anyone could die at anytime</i>	<i>1</i>	<i>1</i>
<i>positive outlook on life</i>	<i>1</i>	<i>1</i>
<i>my fault</i>	<i>1</i>	<i>1</i>
<i>Yes it was a shock right and I was on my own no family, and my ex-husband just neglected me,</i>	<i>1</i>	<i>1</i>

<i>yes, so it was a nightmare, a nightmare</i>		
<i>pressure to have more children</i>	<b>1</b>	<b>1</b>
<i>life could be worse</i>	<b>1</b>	<b>2</b>
<i>How I found out I was positive</i>	<b>1</b>	<b>3</b>
<i>knowing and finding out I was positive</i>	<b>1</b>	<b>1</b>
<i>my husband's illness</i>	<b>1</b>	<b>4</b>
<i>family helped my children</i>	<b>1</b>	<b>2</b>
<i>life back home</i>	<b>1</b>	<b>2</b>
<i>how long will I live</i>	<b>1</b>	<b>1</b>
<i>signs that someone is positive</i>	<b>1</b>	<b>5</b>
<i>being judged</i>	<b>1</b>	<b>2</b>
<i>meeting other Zimbabweans</i>	<b>1</b>	<b>3</b>
<i>trapping men</i>	<b>1</b>	<b>5</b>
<i>grandchildren losing me</i>	<b>1</b>	<b>1</b>
<i>life changed when positive</i>	<b>1</b>	<b>1</b>
<i>trying for a baby</i>	<b>1</b>	<b>2</b>
<i>hard to talk to others am shy</i>	<b>1</b>	<b>1</b>
<i>going home</i>	<b>1</b>	<b>2</b>
<i>protecting others from knowing my diagnosis</i>	<b>1</b>	<b>1</b>
<i>changed since HIV</i>	<b>1</b>	<b>1</b>
<i>having more children</i>	<b>1</b>	<b>1</b>
<i>syphilis in pregnancy</i>	<b>1</b>	<b>3</b>
<i>husband dying of HIV</i>	<b>1</b>	<b>1</b>
<i>sick child</i>	<b>1</b>	<b>10</b>
<i>HIV and my son</i>	<b>1</b>	<b>2</b>
<i>getting treatment at home</i>	<b>1</b>	<b>1</b>
<i>moving to Ireland</i>	<b>1</b>	<b>1</b>
<i>second diagnosis</i>	<b>1</b>	<b>1</b>
<i>doctor talking about HIV in front of her child</i>	<b>1</b>	<b>2</b>
<i>being suicidal</i>	<b>1</b>	<b>1</b>
<i>stress of having a positive child</i>	<b>1</b>	<b>1</b>
<i>doing the best for my child</i>	<b>1</b>	<b>1</b>
<i>waiting for my child to be given the all clear</i>	<b>1</b>	<b>3</b>

<i>disbelief that my child was negative</i>	<i>1</i>	<i>5</i>
<i>testing my older child</i>	<i>1</i>	<i>2</i>
<i>juggling hospital appointments</i>	<i>1</i>	<i>1</i>
<i>I don't want to infect others</i>	<i>1</i>	<i>1</i>
<i>dying from HIV</i>	<i>1</i>	<i>3</i>
<i>private person</i>	<i>1</i>	<i>1</i>
<i>knowing more about HIV condition</i>	<i>1</i>	<i>2</i>
<i>non HIV related illness in children</i>	<i>1</i>	<i>1</i>
<i>both parents are positive</i>	<i>1</i>	<i>1</i>
<i>I don't tell everyone</i>	<i>1</i>	<i>1</i>
<i>slept with one bloke</i>	<i>1</i>	<i>1</i>
<i>who gets HIV</i>	<i>1</i>	<i>1</i>
<i>impact of my diagnosis on others</i>	<i>1</i>	<i>1</i>
<i>things could be worse</i>	<i>1</i>	<i>1</i>
<i>being a volunteer</i>	<i>1</i>	<i>1</i>
<i>support from hospital when had a new a baby</i>	<i>1</i>	<i>1</i>
<i>nurse visiting me at home confidentiality breach</i>	<i>1</i>	<i>1</i>
<i>premature death</i>	<i>1</i>	<i>1</i>
<i>relationship with my children</i>	<i>1</i>	<i>3</i>
<i>My child's father</i>	<i>1</i>	<i>2</i>
<i>Incest</i>	<i>1</i>	<i>1</i>
<i>Johnston's story in South Africa</i>	<i>1</i>	<i>2</i>
<i>I would be dead if I stayed in south Africa</i>	<i>1</i>	<i>1</i>
<i>loneliness</i>	<i>1</i>	<i>3</i>
<i>nephew's disclosure experience</i>	<i>1</i>	<i>2</i>
<i>How I got infected</i>	<i>1</i>	<i>2</i>
<i>impact of HIV diagnosis on my life</i>	<i>1</i>	<i>3</i>
<i>being a drug addict</i>	<i>1</i>	<i>1</i>
<i>advising others to seek help</i>	<i>1</i>	<i>2</i>
<i>telling health professionals about HIV</i>	<i>1</i>	<i>1</i>
<i>trying not to infect the one you love</i>	<i>1</i>	<i>2</i>
<i>biological clock</i>	<i>1</i>	<i>1</i>
<i>family life</i>	<i>1</i>	<i>1</i>

<i>friend support network</i>	<b>1</b>	<b>1</b>

<b>Selective Coding</b>					
<b>First Level Codes</b>	<b>2nd Level Codes</b>	<b>3rd Level Codes</b>	<b>4th Level Codes</b>	<b>Sources Coded</b>	<b>Units of Meaning Coded</b>
<i>being HIV positive</i>					
	<i>coping with HIV</i>			<b>9</b>	<b>26</b>
		<i>loneliness</i>		<b>1</b>	<b>3</b>
		<i>support from others</i>		<b>8</b>	<b>19</b>
	<i>denial</i>			<b>2</b>	<b>8</b>
	<i>HIV illness</i>			<b>3</b>	<b>8</b>
	<i>HIV treatment</i>			<b>6</b>	<b>12</b>
<i>being pregnant</i>					
	<i>possibility of infecting my baby</i>			<b>2</b>	<b>2</b>
	<i>pregnant and HIV positive</i>			<b>5</b>	<b>17</b>
	<i>protecting my unborn child</i>			<b>3</b>	<b>4</b>
<i>HIV diagnosis</i>					
	<i>adjusting to HIV</i>			<b>5</b>	<b>20</b>
	<i>being young</i>			<b>2</b>	<b>2</b>

NARRATIVES OF MOTHERS LIVING WITH HIV

	<i>diagnosis stories</i>			<b>5</b>	<b>10</b>
	<i>first diagnosed</i>			<b>4</b>	<b>7</b>
		<i>bereavement</i>		<b>1</b>	<b>1</b>
		<i>blood donor</i>		<b>1</b>	<b>2</b>
		<i>How I got infected</i>		<b>1</b>	<b>2</b>
	<i>shock of diagnosis</i>			<b>3</b>	<b>3</b>
<b>HIV mothering</b>					
	<i>breast feeding</i>			<b>3</b>	<b>4</b>
	<i>family life</i>			<b>1</b>	<b>1</b>
	<i>having a negative child</i>			<b>4</b>	<b>8</b>
	<i>having more children when positive</i>			<b>2</b>	<b>6</b>
	<i>possibility of being a mother</i>			<b>1</b>	<b>1</b>
		<i>HIV mothering</i>		<b>7</b>	<b>22</b>
	<i>protecting my children</i>			<b>7</b>	<b>30</b>
<b>my children</b>					



NARRATIVES OF MOTHERS LIVING WITH HIV

	<i>my children</i>			<b>10</b>	<b>58</b>
	<i>being HIV positive</i>				
		<i>HIV illness</i>		<b>3</b>	<b>8</b>
		<i>HIV sickness</i>		<b>11</b>	<b>55</b>
			<i>HIV treatment</i>		<b>6</b>
	<i>Disclosure</i>				
		<i>nurse visiting me at home confidentiality breach</i>		<b>1</b>	<b>1</b>
		<i>telling or not telling my children</i>		<b>8</b>	<b>25</b>
		<i>telling others</i>		<b>10</b>	<b>50</b>
			<i>telling partner about HIV</i>		<b>1</b>
		<i>telling or not family about HIV</i>		<b>9</b>	<b>31</b>
<i>positive mothering experiences</i>					
	<i>good experiences of being a mother</i>			<b>2</b>	<b>3</b>
	<i>relationship with my children</i>			<b>1</b>	<b>3</b>

# NARRATIVES OF MOTHERS LIVING WITH HIV

<i>stigma experiences</i>					
	<i>discrimination</i>			<i>7</i>	<i>12</i>
		<i>telling partner about HIV</i>		<i>1</i>	<i>1</i>
	<i>stigma</i>			<i>3</i>	<i>10</i>
	<i>telling health professionals about HIV</i>			<i>1</i>	<i>1</i>